The Enigma of Ovarian Cancer

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Abstract

This qualitative thesis explores the personal experiences of women with ovarian cancer. The issues surrounding non-recognition, symptom reporting, cognitions, reflections and rationalisation for their changing health are complex and central to the thesis. Constructivist psychology is a method of understanding how personal interpretations are constructed by means of individual and subjective experiences. This theoretical standpoint is used as a framework to establish the personal explanations of what the disease meant to the women in this research, and to interpret and understand the perceptions of their interactions with health professionals.

Qualitative data was collected, in two distinct phases; a preliminary pilot with thirteen women analysed thematically and the main study phase with five in-depth face to face interviews, with post-treatment women at similar disease stage. In this phase, the analysis methodology utilised an in-depth, dynamic approach, with interpretative phenomenological analysis (IPA). This phenomenological approach emphasises the use of a small number of participants, with detailed examination of the participant's personal perception of an event. This produces objective statements about life experience and consequences, with an insider perspective gained via empathic and questioning hermeneutics. The results provide an understanding of the personal experience of ovarian cancer.

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CHAPTER ONE

Introduction

This thesis qualitatively explores the personal experiences of women with ovarian cancer from a psychological perspective. The research objective was to determine the women's understanding of what having ovarian cancer meant to them, their cognitive, subjective reflections and their rationalising of changing health are complex and central to the thesis. Rossi and Freeman (1993), argue that the disease journey can only be truly understood and described by the person physically undergoing and using a specialised service, such as surgery, chemotherapy and radiotherapy; and Smith (2004) explains that from a phenomenological perspective, this personal experience can only be revealed by the person cognitively experiencing the event.

The theoretical underpinning of the thesis is focused on the role of language and the interpretation of meaning between individuals. The Constructivist Psychological theories of von Glaserfield (1995), Kelly (1955) and Maturana (1988) are utilised to explain the personal interpretations of women. Maturana's (1988) constructivist psychology explores and discusses how human beings create particular forms of knowledge, why they construct an understanding of situations they explain to themselves and others, *how* and *why* things happen. Maturana views individuals as self organising systems whose ability to construe the world is determined by their psychological structures, and it is these structures which form the basis for the creation of individual realities.

The women in this research had established their own reality about their disease, adopting the 'medical model reality' as they journeyed along their treatment trajectory, often created internal conflicts. Interpretations of 'medical reality' were often exposed to alternative constructions of reality by the women. For example treatments seen as *palliative* by the oncologist were defined as *curative* by the patient. Realities of the same disease and prognosis, were often viewed differently by the patient and doctor.

Loria (1995) suggests all speakers use private languages. Although specific words may be familiar, personal histories influence that way people create unique meanings. The way people (patients) interpret these words and meanings (palliative, incurable, recurrence) is crucial in the subsequent interactions, the so called 'communal choreography' of Efran and Fauber (1995), in the construction of individual lives. This 'communal choreography' instigated via language, forms the characteristics of the 'social dance' that people use to choreograph their lives. This is central to the interactions of the women in this research.

Maturana (1988) describes his position as structural determinism, all changes in an organism (patient) 'are determined by their structure' (Maturana and Varela, 1992). Maturana views these living systems as cognitively closed. As people (living systems) think they are mapping out external worlds, Maturana suggests they are simply experiencing and processing their own structurally determined responses. Features of the external or internal environment (*signs and symptoms of disease*) become important when they 'trigger' changes in the structural dynamics. However, Maturana states, the environment never directly 'instructs' the system about how to behave. Depending on variances and differences of individuality, organisms remain uniquely sensitive or robustly unresponsive to types of environmental stimulation. For example, patients may respond immediately and seek medical help as soon as any symptoms occur, or they may ignore multiple symptoms and be admitted as acute emergencies. Social Constructionists see language as a crucial determinant in how people explain their world and nature of experiences. Gergen (1991) discusses the role of language culturally in power relationships, and within the frame of this thesis, language is critical in establishing information as a communication process between individuals (patients, relatives, health professionals etc). For women in this research, establishing their own reality about their disease was often a means of denial, refusal to accept medical truths. Misunderstandings about prognoses or denial to family needed considerable assimilation for cognitive equilibrium. Some of the women and their partners had constructed an elaborate 'alternative reality' to sustain each other through a traumatic period.

The theoretical perspective of constructivist psychology is complimented by utilising the analytic technique of interpretative phenomenological analysis (IPA). IPA is primarily concerned with understanding how individuals make sense of their lived experiences and the meanings they attribute to events and occurrences in their lives. It is phenomenological in that it attempts to explore an individual's personal perception or account of an event, as opposed to attempting to produce an objective record of the event itself (Smith, 2004).

The emphasis is also on *quality* of data rather than *quantity.* Smith qualifies this psychological approach as inherently different from other quantitative discursive methods, in that it seeks to develop an in depth understanding of the participant's world through interpretative activity involving researcher and participant. Thus, it is not looking or *comparing* for example, themes identified through several patient responses to developing ovarian cancer; instead IPA is seeking to develop a detailed case analysis *as and end in itself.* It may, involve comparing other similar detailed case studies, but its main theoretical stance is not grounded in the identification and comparison of generalisations of comparable cases. It is the *specificity* and detail of idiographic detail and analysis relating to personal interpretation that is the essence of IPA.

A review of the literature indicated that published peer reviewed research had not used IPA to explore the experiences of women with ovarian cancer before. This methodological approach was utilised in the main phase of this research, with in-depth interviews and analysis undertaken in order to explore how the women tried to understand and make sense of ovarian cancer. For the women, their experience of cancer was beyond normal perceptions and comprehensions. This changed cognitions and perceptions in many ways, including relationships, family, work and reflections on mortality and is discussed in detail in the thesis.

CHAPTER 2

Literature Review

2.1. Introduction

The thesis presents a qualitative analysis of the perceptions of women with ovarian cancer and their changing health, rationalisation and cognitions. The literature review therefore will present relevant literature that describes the psychologically based theoretical framework for the thesis and discuss qualitative research. In particular, an analysis technique rapidly gaining popularity in qualitative health psychology research, which focuses on understanding how individuals make sense of their personal and social world. Interpretive phenomenological Analysis (IPA) focuses on the interpretation individuals give to their personal experiences, events and cognitions. In addition, a critical appraisal of empirical qualitative research literature on women with ovarian cancer was undertaken and how this literature was identified and appraised will be discussed first

2.2. Critical appraisal, review methodology and qualitative synthesis

Critical appraisal is a method of systematically examining research to judge its trustworthiness, value and relevance in relation to a particular issue. Qualitative research is relevant to explore the experiences and meanings of women diagnosed with ovarian cancer. Rigour, credibility and relevance are three broad areas that need to be considered when appraising qualitative research (CASP, 1998, 2006; Miles and Huberman, 1994; Silverman, 2006).

Within qualitative research, data synthesis is a contentious issue as there are a number of varying viewpoints as to the nature and purpose of qualitative research (Campbell et al, 2003). There is also some contention as to the acceptability of the synthesis of qualitative studies, derived from different traditions (Sandelowski et al, 1997). Dixon-Woods et al (2005) indicate that the most difficult synthesis is of qualitative and quantitative findings, with one data form being converted for synthesis i.e. qualitative into quantitative. It has been noted that studies be synthesised only if they share a similar methodology (Jenson et al, 1996; Estabrooks et al, 1994). This suggests that even when similar themes are identified across studies, the mixing of methods lead to difficulties in developing theory, due to epistemological foundations. Paterson et al (2001) propose that different approaches can use meta-method and meta-theory to overcome some difficulties.

Cambell et al (2003) suggests that synthesis of qualitative research studies can be advantageous, especially when related to evidence based practice and patient care or treatment. Techniques for systematically reviewing quantitative literature draw on a 'rationalist' model, generally concerned with effectiveness which is inappropriate to qualitative methodology (Dixon-Woods et al, 2006). There are different approaches to reviewing qualitative data; aggregative review focuses on summarising and describing data and interpretative review which uses data to develop concepts and theories (Dixon-Woods et al, 2006).

Barbour (2001) claims that aggregate or checklist criteria for determining quality are counter to the ethos of qualitative research and do not in themselves confer rigour. In addition, multiple reviewer agreement for checklists is variable (Dixon-Woods et al, 2006). Guidance on narrative synthesis (Popay et al, 2006) directs the researcher to an interpretive narrative review.

An interpretive narrative review was undertaken to review qualitative studies of women's perspectives in ovarian cancer. Dixon-Woods et al (2005) purport that narrative reviews often lack transparency and Meyrick (2006) state that transparency in the process is important in order to determine quality. Therefore, this review will detail each stage of the process for transparency.

2.3. Obtaining the qualitative literature on women's experiences of ovarian cancer

The research was undertaken from a qualitative behavioural sciences perspective. The literature review was undertaken to identify prior published qualitative research on the personal experiences of women with ovarian cancer. In order to obtain relevant and the most up to date literature, a search for relevant published research was undertaken in May, 2009.

The literature search was undertaken using University of Liverpool access to databases, such as *Ovid, Proquest, Psychlit, Medline* and *Web of Knowledge.* Table 2.1 provides an example of a search procedure. The number of qualitative papers obtained was maximised by using the search terms 'qualitative' and 'ovarian cancer'.

Table 2.1: Sample literature search - Web of Knowledge

Date undertaken: 01/05/2009
Access: Web of Knowledge all databases selected
Topic=(qualitative) AND Topic=(ovarian cancer)
Timespan= 1990 – present

2.4. Method

Electronic search strategy

Literature searching for qualitative research and systematic reviews should cover the majority and minority views in the area, draw on a range of disciplines and use complimentary electronic and manual searches (Booth, 2001; Dixon-Woods et al, 2006). Searches in PsycINFO, PubMed, Web of Science (ISI), EMBASE, MEDLINE and Cochrane Library using keywords 'qualitative' and 'ovarian cancer' were carried out on 1/05/2009.

A total of 83 papers were obtained, however a number of these were not relevant as they focused specifically on genetic screening. By adding *not genetic* to the search terms, the number of identified papers reduced to 17. Identified papers were noted to be recent from the years 1997 to 2008, with 11 of the papers being from 2004 onwards.

All papers were obtained and evaluated for inclusion, of the identified papers, 3 were excluded due to lack of relevance, as although qualitative studies they did not report (or include at all) the experience of women with ovarian cancer. The 3 excluded papers focused on communication problems between the GP and hospital (1), the experience of families (1) the experience of husbands (1). A total of 14 papers were found to meet inclusion criteria 1-3 (see table 2.2) and were included in the narrative review.

Table 2.2: Inclusion and exclusion criteria

Inclusion Criteria
i) Journal papers published in English between January 1990 and May 2009. ii) Empirical research studies stating qualitative methods used to explore experiences of women with a diagnosis of ovarian cancer. iii) Qualitative research on women with a diagnosis of ovarian cancer in their own words (i.e. exclude only questionnaire or closed question interviews).
Exclusion strategy
Exclusion stage 1 Papers were excluded in the first instance if they did clearly not meet any of inclusion criteria 1,2 or 3. The remaining 17 papers were obtained in full.
Exclusion stage 2 Reading of the full paper revealed that a further 3 papers did not meet inclusion criteria 1,2 or 3 (Appendix 1 for papers included or excluded).
Final total of included papers for narrative review A total of 14 papers were found to meet inclusion criteria 1-3 and were included in this review (Appendix 1 for papers included or excluded).

2.5. Recognition of possible non-identified papers

It should be noted that some relevant research might not have been obtained, as electronic indexing of qualitative studies has been reported as being problematic (Dixon-Woods et al, 2006). However, manual searches of some potentially relevant journals was also undertaken to try and identify other relevant papers for example *Qualitative Health Research*, *European Journal of Women's Studies.* Reference lists of the included papers were also reviewed to identify any other missed research.

2.6. Identifying unpublished studies - the gray literature

Utilising any gray literature in preparing a *systematic review* is considered important to alleviate publication bias and can include a consideration of various sources for inclusion such as theses, conference proceedings and clinical trials registries. In this thesis a *narrative review* of the qualitative literature was undertaken, however considering any theses or dissertation published in the area of ovarian cancer could possibly contribute to the narrative review. The inclusion criteria numbers 2 and 3 and all exclusion criteria detailed in table 2.2 were used to consider inclusion suitability. The University of Liverpool's electronic *ProQuest* database was searched on 3rd May, 2009 for theses awarded in any year, using the search terms 'qualitative' and 'ovarian cancer'. Four theses were identified, of which 3 were rejected. The rejected theses focused on nurse perceptions as opposed to the perceptions of women (2) and issues for organisations to consider in women returning to work, following treatment for ovarian cancer (1). The remaining thesis was obtained, further investigation revealed that a research paper had been published (Power, Brown and Ritivo, 2008) in a peer reviewed journal from the thesis findings; this was obtained and included in the narrative review as it met the inclusion criteria.

2.7. The narrative review

Paper acquisition

To inform the review process a data extraction form (appendix 2) was used to collect data. The form was based on discussion and recommended criteria for assessing quality in qualitative research (Popay et al, 200; CASP, 1998, 2006; Campbell et al, 2003; Sandelowski, Docherty and Emden, 1997,). A grid comparing the papers was constructed (table 2.3).

Identifying themes and developing a preliminary synthesis

Descriptions, groupings, data translation and tabulation were considered appropriate. A grid was constructed to identify common and contrasting themes and outcomes from the papers (table 2.3). In order to explore how these themes related to one another an attempt was made to translate them into one another such that none were lost and none repeated. A taxonomy of issues was inductively developed from the papers. This was refined using techniques similar to the axial and selective coding used in grounded theory (Glaser and Strauss, 1967). Identified issues will now be discussed.

2.8. Narrative review discussion of included papers

It was found that there were discrepancies and missing information in the papers and as Meyrick (2006) noted, in some cases a lack of understanding with qualitative philosophy and methodology. Table 2.3 presents a summary of papers included in the narrative review.

Table 2.3: Papers included in the Narrative Review

Author	Sample	Data collection method	Analysis and theoretical perspective	Main findings
1. Akyuz, A.; Guvenc, G.; Ustunsoz, A. and Kaya, T. (2008) Living with gynecologic cancer: Experience of women and their partners *Journal of Nursing Scholarship.* 40 (3):241-247	19 Turkish women with gynecological cancer Aged 43-70 years (and 12 partners aged 46-73 years) Recruited over a 4 month period. The women were diagnosed with endometrial, ovarian, cervical and corpus uterine cancers. Time from diagnosis to interview 6 months to 10 years.	Data obtained via open-ended, in-depth, audio-taped interview, which lasted approximately 35-45 minutes each. Interviews of women and husbands, undertaken separately, by the same interviewer.	Descriptive phenomenological approach, based on Colaizzi's methodology was applied to transcripts. Meanings transformed into clusters of themes using thematic analysis. 7 main themes were identified.	*Findings:* 7 themes identified: • experiences during the diagnosis period • experiences during the treatment period • the effect of cancer on family life • changes in daily life • coping methods and support sources • the meaning of illness • experiencing the illness as a woman *Reflexivity discussed?* No *Qualitative issues discussed?* • To ensure credibility of data, transcripts read in order by each researcher • Themes identified individually by each researcher and then cross referenced by team. Differences discussed and final agreements made • Four informants randomly selected

				and asked to read descriptions *Findings transferable?* Sample non-random and cannot be generalized
2. Elit, L.; Charles, C.; Gold, I.; Gafni, A.; Farrell, S.; Tedford, S.; Dal-Bello. D. and Whelan, T. (2003) Women's perceptions about treatment decision making for ovarian cancer *Gynecologic Oncology* 88 (2):89-95.	21 Canadian women with advanced epithelial ovarian cancer, who had recently undergone surgery Between June, 1999 and February, 2001. Oncologists and cancer centre staff also approached patients and recruited.	In depth semi-structured interviews in patient's home. Experienced interviewer undertook all interviews. Interviews, audio-taped and transcribed.	Qualitative study based on guidelines from BMJ and American Medical Association. Content analysis developing themes. NVivo used to facilitate coding.	*Findings:* Five themes identified: • Knowledge of treatment benefits and risks • Readiness to make a decision • Perceptions of treatment choice • Physician-patient relationship • Social supports *Reflexivity discussed?* No *Qualitative issues discussed?* • Discuss inclusion/exclusion criteria • Discuss pilot and revisions • Each transcript coded independently by 2 members of team, discrepancies resolved through discussion *Findings transferable?* Yes

3. Ersek, M.; Ferrell, B.R.; Dow, K.H.; Melancon, C.H. (1997) Quality of life in women with ovarian cancer *Western Journal of Nursing Research* 19 (3):334-350	Women recruited from mailing lists of 2 organisations. 152 women in all ovarian cancer disease stages agreed to participate.	Qualitative data collected by asking participants to write their definitions and experiences of quality of life since their diagnosis. Qualitative analysis elaborates the four domains of Ferrell's QOL model: physical, psychological, social, and spiritual well-being. Quantitative data collected using the QOL-Cancer Survivors tool and demographics.	Mixed data analysis. Qualitative data analysed using content analysis. Quantitative data coded and verified using CRUNCH software. Quantitative analysis used descriptive statistics.	*Findings:* • QOL is moderately high for this group of cancer survivors, despite some specific negative facets of the illness and treatment experience. *Reflexivity discussed?* No *Qualitative issues discussed?* • All data analysed and sent to other researchers for independent verification • Revised themes and data sent to researchers and to a nurse and patient for assessment of validity of themes *Findings transferable?* Yes

4. Ferrel, B.R.; Smith, S.R.; Ervin, K.S.; Itano, J. and Melancon, C. (2003). A Qualitative analysis of social concerns of women with ovarian cancer. *PsychoOncology* 12: 647–663	Communications from a support newsletter - '*Conversations*', for American ovarian cancer sufferers. Text from the women contained in 21,806 letters, cards, and emails Received over an 8 year period.	3,566 comments obtained, relating to QOL issues: 776 social well being 677 physical well being 1352 to psychological well being 687 to spiritual well being	Ethnographic content analysis 4 stages: • processing raw data • data reduction • data display • conclusion drawing and verification Analysis guided by City of Hope, Quality of Life Model.	*Findings:* Four main themes identified • physical • psychological • social • spiritual and quantitative findings reported from the City of Hope QOL ovarian cancer instrument. *Reflexivity dscussed?* No *Qualitative issues discussed?* • Validation discussed • Final tables reviewed by external nursing consultants with extensive backgrounds in ovarian cancer • Quantitative evaluation also undertaken • Limitations discussed *Findings transferable?* No
5. Ferrell, B.; Smith, S.; Cullinane, C.	Text from 21,806 letters, cards, and	677 comments written by	Ethnographic qualitative research subjected to	*Findings:*

and Melancon, C. (2003) Symptom concerns of women with ovarian cancer *Journal of Pain and Symptom Management* 25 (6):528-538	e mails written by American women with <u>ovarian</u> cancer. Comments were posted in a newsletter for ovarian cancer patients. Received over an 8 year period	women with ovarian cancer were evaluated looking for themes. All were anonymised and were personal letters and comments submitted to a newsletter.	<u>content analysis</u> Meaningful comments in the data were bracketed and coded within physical, psychological, social, and spiritual domains according to the City Hope QOL-Ovarian Cancer instrument.	• Distress over delayed diagnoses given the presence of pre-diagnosis symptoms • Frequently described post-diagnosis symptoms included pain, fatigue, gastrointestinal effects, and menstrual and fertility changes *Reflexivity discussed?* No *Qualitative issues discussed?* • Validation discussed • Limitations discussed as problems with limited analysis, advanced disease and end of life care under represented and possible bias of study *Findings transferable?* No
6. Ferrell, B.; Smith, S.L.; Cullinane, C.A. and Melancon, C. (2003) Psychological well	A review of 21,806 letters, cards, and e-mails reflecting correspondence from January 1994	A total of 1282 comments were identified relating to psychological well being	<u>Ethnographic</u> qualitative research methods Statements related to the impact of disease were bracketed and coded within physical,	*Findings:* • Many descriptions of stressors associated with disease status. • Significant stressors were identified within all phases of diagnosis, treatment, remission, and recurrence.

being and quality of life in ovarian cancer survivors *Cancer* 98 (5):1061-1071	to December 2000 between American ovarian cancer survivors		psychological, social, and spiritual domains according to the City of Hope Quality of Life Ovarian Cancer instrument.	Women described both positive and negative effects of disease and frequently demonstrated resourcefulness and perseverance by sharing coping mechanisms and survival strategies. *Reflexivity discussed?* No *Qualitative issues discussed?* • Limitations discussed briefly, analysis limited due to inability to relate findings to demographic or disease data • Also suggests bias as higher literate women would write to newsletter *Findings transferable?* No
7. Howell, D.; Fitch, M.I. and Deane, K.A. (2003) Impact of ovarian cancer perceived by women	18 Canadian women with advanced ovarian cancer. Recruited to study by nurses and gynaecologists at 2 hospitals.	Telephone interviews guided by interview schedule lasting 1 hour. Recorded and transcribed.	Qualitative study examined the perspectives of women living with ovarian cancer Interview transcripts were read by 3 authors and compared and	*Findings:* • Life changes • Major challenges • Support *Reflexivity discussed?* No *Qualitative issues discussed?*

Cancer Nursing 26 (1):1-9	Participation invitation also given to local ovarian cancer support group.		discussed. Data coded and subjected to thematic analysis	- Validity discussed - Information derived from interview cross referenced with diagnosis data. *Findings transferable?* No
8. Howell, D.; Fitch, M.I. and Deane, K.A. (2003) Women's experiences with recurrent ovarian cancer *Cancer Nursing* 26 (1):10-17	18 Canadian women with advanced ovarian cancer. Recruited to study by nurses and gynaecologists at 2 hospitals. Participation invitation also given to local ovarian cancer support group.	Telephone interviews guided by interview schedule lasting 1 hour. Recorded and transcribed.	Qualitative study examined the perspectives of women living with ovarian cancer Interview transcripts were read by 3 authors and compared and discussed. Data coded and subjected to thematic analysis	*Findings:* - *Waiting for recurrence* - Facing the diagnosis of recurrence - Managing treatment related concerns - Attempting to regain control *Reflexivity discussed?* No *Qualitative issues discussed?* - Sample bias - Not generalisable *Findings transferable?* No
9. Pilkington, F.B. and Mitchell, G.J. (2004)	Purposive sampling of 14 Canadian women diagnosed with	Semi-structured interviews. Tape recorded	A qualitative, descriptive-exploratory method used with Parse's human	*Findings:* Four themes identified quality of life - Treasuring loving expressions

Quality of life for women living with a gynecologic cancer *Nursing Science Quarterly* 17 (2):147-155	gynecologic cancer, including ovarian. Age range 30-73, average 50 years. Participants ranged from those recently undergone cancer surgery to those who had lived with cancer for several years. Recruited at hospital by nurse, and consented by researcher.	and transcribed. Duration from 20 minutes to 2 hours	becoming theory provided the theoretical perspective. Through analysis-synthesis process themes were identified.	• Affirming personal worth • Consoling immersions amid torment • Expanding fortitude for enduring *Reflexivity discussed?* No *Qualitative issues discussed?* • Findings enhance theoretical perspective chosen *Findings transferable?* Yes
10. Power, J.; Brown, L. and Ritvo, P. (2008) A qualitative study examining psychosocial distress, coping, and social support	30 Canadian ovarian cancer patients. Age range 37-79 years, average 59 years. Convenience	Women given option of face to face or telephone interviews. 27 opted for phone interviews	Grounded theory approach, with constant comparison technique used to analyse each transcript. Content analysis to identify all possible variations to generate	*Findings:* *Five main themes identified:* • Extreme blunting • Having a forgotten cancer • Traumatic surprise of diagnosis • Highs and lows of healthcare • Support gap experienced post

across the stages and phases of epithelial ovarian cancer *Health Care for Women International* 29 (4):366-383	sample. Identified via gynaecology oncology clinic and recruited to study by treating oncologist. Various stage of disease, from those with recurrence having undergone several cycles of treatment, to those more than 1 year post-treatment.	3 attended for face to face interviews. Audiotaped and transcribed. Interview consisted of structured sections of medical history; experience of depression, anxiety; coping and Dr/ patient communication.	systematically based theory and hypotheses of principle investigator. Saturation was stated to have been reached after 30 interviews.	diagnosis. *Reflexivity discussed?* No *Qualitative issues discussed?* • To ensure standardisation of interviews by different interviewers, transcripts were read by second interviewer, who also received instruction from first interviewer regarding technique etc. • 20% of transcripts checked for accuracy by team members. • Length of interview not viewed as important; short interviews often generated equally as important information, but more concisely presented. *Findings transferable*: Yes
11. Smith, A. (2008) Whisperings of Ovarian Cancer: Acknowledging	379 posted 'stories' on 2 American and Canadian ovarian cancer web sites	Website posted personal stories recounting impact of diagnosis of ovarian cancer.	Women's Ways of Knowing (WWK) Belenky et al (1997), A theoretical framework grounded in the	*Findings*: Signs and symptoms related to: • Silence • Received Knowledge • Subjective knowledge

Women's Voices *Clinical Journal of Oncology Nursing* 12 (6):913-920	Of which, 135 were from women with ovarian cancer, rest were husbands, daughters, sons, nieces, brothers and friends.		analysis. A phenomenological approach looking at women's points of view on life and learning. This was applied to a descriptive, qualitative study using content analysis looking at the personal stories on the ovarian cancer websites.	• Procedural knowledge • Constructed knowledge. *Reflexivity discussed?* No *Qualitative issues discussed?* • Limitations of using personal stories. • Limitations of using content analysis. *Findings transferable?* Yes
12. Swenson, M.M.; MacLeod, J.S.; Williams, S.D.; Miller, A.M. and Champion, V.L. (2003). Quality of living among ovarian germ cell cancer survivors: A narrative analysis [Online exclusive]. *Oncology Nursing Forum*	109 American women. Age range 19-64 (median 36 years) Diagnosed with germ cell ovarian cancer. Specifically women enrolled in prospective clinical trials of cisplatin based chemotherapy	Background questionnaire and telephone interviews. Questions were asked from 7 different QOL scales At interview end participants were asked 4 semi-structured questions.	Qualitative constructivist paradigm. The text of each interview was assigned content labels to identify meaning units. Labels were focused on content at this early level, rather than attempting early interpretation. Both researchers read all transcripts and coded each independently. They then met to discuss and reach	*Findings:* 4 themes identified: • Celebrating illness • Experiencing empathetic affirmation • Mourning loss • Valuing illness *Reflexivity discussed?* No *Qualitative issues discussed?* • Authors did not design questions and were not involved in interviews, thus felt their connection was 'loose'. Only directly involved in the 4 qualitative

30 (3): 48-54 From http://www.ons.org/publications/journals/ONF/Volume30/Issue3/3003380.asp	after surgery and disease free for at least 2 years. Recruitment was from 42 sites.	Following 25 interviews, these 4 questions were reviewed and made more open ended.	consensus about code labels. Throughout this reiterative process, the labelled groups were collapsed into subthemes and reflection continued during this constant comparison phase of the qualitative analysis. The researchers developed four themes representing constructions regarding the shared meanings from the narrative responses.	questions for analysis • The only qualitative questions were asked at the end of a long and tiring interview • Participant answers could have been influenced by prior structured questions • Due to the subjective nature of qualitative description, the findings cannot be generalised *Findings transferable?* Possibly Stated that findings may possibly be transferable to other patients and settings.
13. Wray N.; Markovic, M. and Manderson, L. (2007) Discourses of normality and	52 Australian women. Age range 27-80 Diagnosed with	Interviews were open ended and narrative Duration up to 90 minutes.	3 year qualitative study utilising grounded theory. Atlas-ti software used to assist with thematic analysis.	*Findings:* • Cancer identity • Taboo of cancer site • Understanding treatment • Seeking support

difference: Responses to diagnosis and treatment of gynaecological cancer of Australian women *Social Science and Medicine* 64 (11):2260-2271	gynaecological cancer, including uterine, <u>ovarian</u>, vulval and cervical cancers. Time elapsed since diagnosis to 5 years. Purposive sampling to increase ethnic diversity of study participants. 27 Australian born and 25 overseas born.	Conducted in language of women's choice, majority conducted in English.		*Reflexivity discussed?* No. *Qualitative issues discussed?* • Data collection and analysis performed concurrently, in order to modify interview guidelines to accommodate new emerging themes. • Comparative data analysis on all transcripts identified similarities and differences. *Findings transferable?* Yes.
14. Ziebland, S.; Evans, J. and McPherson, A. (2006) The choice is yours? How women with ovarian	43, UK women diagnosed with <u>ovarian</u> cancer. Age range 33-80, median 54 years. A maximum variation sample	Qualitative interviews were conducted in the UK, with women with ovarian cancer over a twelve month period.	A qualitative software package (Nvivo 6) was used to help with the organisation and retrieval of the data. <u>Thematic</u> qualitative analysis was used to explore emergent and	*Findings:* Women did not always recall being involved in decisions Some felt there had been no 'real' decisions to make or said they preferred their medical team to decide on their behalf. Other women described asking questions and seeking second opinions, but still 'going

cancer make sense of treatment choices. *Patient Education and Counselling* 62: 361-367	was utilised in order to reach a broad range of ovarian patients. Included women from different geographical areas and treatments. Women who were well and those who had relapsed.	Recruited via a support group newsletter, GP's, hospital consultants and specialist nurses. Interviews were semi-structured. Tape recorded and transcribed.	anticipated themes across the data set. Constant comparison used to ensure analysis was representative of the data.	along with' their doctor's recommendation. A few women said that they had learnt enough to take control, or make at least some of their own treatment decisions. *Reflexivity discussed?* No *Qualitative issues discussed?* • A small study based on women's descriptions in interview • Interview sometimes a few years after diagnosis • No observations of clinical encounters • No clinician perspectives *Findings transferable?* Yes

Narrative review findings

Overview

In the narrative review, 14 papers met the inclusion criteria and were included; these were from five countries (United Kingdom - 2; USA - 5; Canada - 5; Australia - 1 and Turkey - 1). The studies varied in terms of focus and inclusion of ovarian cancer; some included aspects of all gynaecologic cancers (Acyuz et al, 2008; Wray et al, 2007); others were specific as to type of ovarian cancer (Power et al, 2008, Swenson et al, 2003); others looked at only recurrent ovarian cancer (Howell et al, 2003).

Sample

This varied from 14 face to face interviews (Pilkington and Mitchell, 2004), to 109 questionnaires and telephone interviews (Swenson et al, 2003). In addition, the analysis of 21,806 letters, cards and emails from women in their own words formed the basis of three papers (Ferrell et al, 2003).

All papers were country specific, with no international studies. Data collected via:

- local geographic area (5/14),
- multiple sites (5/14),
- Internet based (4/14).

Recruitment to studies were undertaken by nurses in clinics, consultants in clinics or by direct mailing from researchers following access of various databases, newsletters, ovarian cancer support networks or websites.

Data collection method

Data was collected by:

- Face to face interviews (5/14), using semi structured interview questions, encouraging the participants to lead on areas they saw as important; these were audio recorded and transcribed.
- Telephone interviews were used in three (3/14) studies, all audio recorded and transcribed.
- Choice offered of face to face interview or telephone (1/14), using semi structured interview questions, encouraging the participants to lead on areas they saw as important and audio recorded and transcribed.
- Postal questionnaires (1/14) that encouraged participants to include their own narrative of experience, rather than just closed questions.
- Data from ovarian cancer websites or support newsletters (4/14). Patient consent was highlighted as an issue and all articles cited the anonymisation of data a particular consideration. Authors stated this information had been posted on a web site, but did not specify if names were on website.

Three of the papers from websites or newsletters (Ferrel, Smith and Ervin et al, 2003; Ferrell, Smith and Cullinane et al, 2003; Ferrell, Smith, Cullinane and Melancon, 2003) reported in excess of 21,000 cards, letters and emails from women with ovarian cancer used as data. Writing to all participants for consent would have been extremely difficult or impossible as the data had been written over a period of 8 years.

Time between diagnosis and interview was reported as from shortly after diagnosis to 10 years. In some articles (i.e. Akyuz et al, 2008), the question of memory recall and patient reflection is an important issue. The reconstruction of personal history over a ten year period may be substantial, making comparison with research with a shorter time-period to interview difficult. Other studies also looked at relapsed, as well as newly diagnosed women (Ziebland et al, 2006) with different treatments, different survival times, and different geographical areas. Issues regarding heterogeneity and generalisability should always be considered when comparing with other research.

In terms of the duration, the interviews lasted from 20 minutes to two hours. Data collection also varied with telephone interviews being used or offered (4/14) in some studies. Power et al (2008), suggests this style of data collection awards greater participant privacy, with less pressure to answer questions over the telephone, when compared to face to face interview. Power et al views the telephone interview as providing a greater option for the withholding sensitive information and excluding any intimate discussion that participants may not wish to discuss. However, during a face to face interview, a skilled interviewer should be able to identify if the participant is becoming uncomfortable with a line of questioning via non-verbal communication or general speech tone or inflection (such as throat clearing, restlessness, emphasis, etc). No mention is made by Power et al regarding the importance of non-verbal communication and the consequential loss of this during telephone interviewing. Power et al did report of the thirty women agreeing to be interviewed, twenty seven chose telephone interview, with only three selecting face to face interview.

Analysis and theoretical perspective

Different perspectives for the qualitative studies were cited:

- Thematic analysis - Four (4/14) studies cite thematic analysis was used and cite the main themes that emerged, but only mention data 'coded' without expansion on how this was done. One study by Akyuz et al (2008) uses this approach and explicitly discusses a phenomenological framework, based on Colaizzi's methodology. Zeibland et al (2006), mention the use of Nvivo 6 software to help with organization and retrieval of data themes.
- Grounded theory – two studies (2/14) cite grounded theory, with Wray et al (2007) mentioning the utilization of Atlas–ti software to assist with coding. Wray et al (2007) and Power et al (2008), give an expansive account of their application of the process of grounded theory.
- Content analysis – seven studies (6/14) used content analysis with Elit et al (2003), stating guidelines from the Britsh Medical Journal and American Medical Association were used for their analysis, together with NVivo software to facilitate coding. Ersek et al (1997) and Swenson et al (2003), discuss the actual process of the analysis, discussing its limitations. Ferrel et al (2003) cites ethnographic qualitative research subjected to content analysis based on City Hope

QOL- Ovarian Cancer Instrument.

- Other analysis methods unspecified – (2/14) Pilkington & Mitchell (2004), describe a qualitative descriptive exploratory method used with Parse's Human Becoming theory as the theoretical perspective, producing themes, but this does not specify exactly the type of analysis undertaken. And Swenson et al (2003) report a 'qualitative descriptive design based within constructivist paradigm' with content labels, constant comparison and themes produced.

A detailed analysis account was provided in the majority of studies:

- Thirteen studies (13/14) provided a rigorous account of their choice of theory and the application, expanding on justification and efficacy of results.
- One (1/14) study did not give a rigorous account (Ziebland et al 2006).

Research findings

Findings highlighted three specific areas of the disease trajectory:

1. Experiences around diagnosis period

Nine (9/14) studies discuss issues pertinent to delayed diagnosis, quality of life, psychological and physical impact; with Elit et al (2003) and Ziebland et al (2006) specifically examining the decision making of the women and their relationship with their doctors. All (14/14) discuss the meaning and impact of the disease to the women themselves, including the knowledge base on ovarian cancer and insight into treatment. Three studies (3/14) included interviews and opinions from partners, family and friends (Akyuz et al, 2008;

Ferrel et al, 2003; Smith 2008).

2. Disease progression and fears of recurrence

Ferrel et al (2003), Howell et al (2003), Power et al (2008), all examine women's perceptions regarding disease recurrence. Eight studies (8/14) cite incidence of recurrence, but not from women's personal perspective. Two discuss the impact of disease on sexuality; Smith (2008) from the women's perspective and Akyuz et al (2008) includes the woman and her husband or partners perspective. All papers examine quality of life; two (2/14) concentrate on physical symptoms; twelve (12/14) developed analysis on the importance of psychological interpretation, as women lived with the disease.

3. Terminal disease

Six (6/14) papers discuss advanced/terminal disease and specifically mention spirituality, waiting for recurrence, mourning loss, valuing illness, attempting to regain control (Ferrel et al, 2003; Smith, 2008; Howell et al, 2003; Swenson, et al, 2003, Ersek et al, 1997; Elit et al, 2003).

Qualitative issues

All studies discussed methodological issues involved in the studies and some (6/14) mention study limitations. Wray et al (2007), discusses lack of experience of interviewers, naivety regarding cancer issues and the risk of emotional involvement if interviewers are involved in longitudinal study. Three of the papers extracted data from websites or newsletters (Ferrel, Smith and Ervin et al, 2003; Ferrell, Smith and Cullinane et al, 2003; Ferrell, Smith, Cullinane and Melancon, 2003) and reported on in excess of 21,000 cards, letters and emails from women with ovarian cancer. This caused problems; these studies reported that advanced disease and end of life care was under-represented and that analysis was limited due to an inability to relate the findings to demographic or disease data. Swenson et al (2003) stated that they were not involved in the questionnaire design or the interview process and felt disconnected, as they were only involved in the final semi-structured, qualitative questions. This highlights the importance of involvement and ownership of the research, when the team involves several members.

Validity and reliability are discussed in the majority of (13/14) studies, with variation in the reporting of details regarding independent raters, participant validation methods, lack of transparency, credibility and triangulation (8/14). Only one study (1/14) discussed deviant cases and nine (9/14) considered transferability. Most studies (13/14) detailed sampling and data collection and discussed the limitations and shortcomings of their method. Only eight (8/14) provided a detailed discussion of the analysis process and theoretical issues. Validation was mentioned briefly (12/14) in most studies. In eight (8/14) studies, detail was provided on the role of independent raters. Few studies (3/14) discussed participant validation, data credibility, triangulation, lack of transparency or possible improvements to future studies.

Swenson et al (2003), provided discussion on theory construction, as opposed to quality of data collection; the authors concluded that the questionnaire was too restrictive and this impacted on the quality of data collected in terms of richness of data. In addition, due to an omission of their ethics application, they were unable to validate the questionnaire responses by cross-referencing with participants. Swenson et al report that future research questions will be designed to be open ended, with quantitative data distinctly separated from the phenomenological qualitative data collection, Furthermore, Swenson et al recognises that by including the qualitative questions as an 'add on' to a long telephone questionnaire, data collected was not as rich as it could have been.

Reflexivity

Only the Wray et al (2007) article discussed reflexivity (1/14), with none of the other studies discuss how the researcher reflected upon their positions during the interview process, transcript reading or analysis and how this may have impacted on their findings. Ten of the studies involved participant contact via face to face interview or telephone interview with women with ovarian cancer, this level of contact and the subject matter would have required some degree of reflexivity. It is possible that due to the paper length there was not enough space to discuss this issue in detail, however some comment should have been made.

In terms of the duration of the interview, Swenson et al (2003) and Howell et al (2003), reflected that that final interview questions may have been answered better had they been introduced earlier in the interview, when both interviewee and interviewer were more alert. The quantitative questions tended to be asked earlier in the interview and Swenson et al suggested that by the time participants were asked for their personal opinions and reflections, they were too tired. In addition, the researchers suspected that they also have been influenced by the previous quantitative questions. Whilst the question of tiredness can also be related to face to face interviews, it is easier to motivate people and keep interest whilst in conversation, rather than being displaced and rather 'faceless' on the end of a telephone. Whilst phone interviewing may be quicker, cheaper and more convenient, the value and validity of data may be compromised, or not as rich as it may have been when compared to that obtained via face to face interview.

Transferability of findings

Nine studies commented on research transferability, only four (4/14) discussed in detail outlines for further research. Furthermore, eight studies (8/14) cited caution in transferability due to small sample size. Replication of the studies would, to some extent be feasible from supplied details. However, four would be particularly problematic. Three studies (Ferrel, Smith and Ervin et al, 2003; Ferrell, Smith and Cullinane et al, 2003; Ferrell, Smith, Cullinane and Melancon, 2003) collected unique data, in terms of the volume of data (21,000 text items written by women) and the length of time collected (8 years). The fourth study (Akyuz et al, 2008), collected data from participants up to ten years post-diagnosis.

Conclusion

The majority of studies demonstrated weaknesses in methodological rigor. A constant criticism aimed at qualitative method is the lack of transparency and failure to validate and substantiate data, within a qualitative methodological coherent framework. This was evidenced in the studies included in the narrative review; with undefined terminology regarding theoretical application i.e. grounded theory *type* or grounded theory *approach*, *coded themes* or *themed analysis,* poor description of methodology and implicit rather than explicit meaningful criteria. Reviewing the studies provided substantial information from various perspectives i.e. face to face interviews, telephone interviews, letters and emails, questionnaires and utilised these opinions from women at all stages of disease. Data analysis also demonstrated different methods and theoretical perspectives, which produced a multiplicity of results and diversity of theoretical application.

2.9. Summary of narrative review

The narrative review has discussed prior qualitative research on the experiences of women with ovarian cancer. It was noted that none of the papers reviewed used IPA for analysis. Findings from this research will therefore also contribute to the growing body of research on the use of IPA in health psychology.

2.10. Other relevant literature

The literature reviewed in this section discusses areas of importance in understanding the qualitative experiences of women from a behavioural sciences perspective. The literature to be discussed is embedded within a psychological framework and discusses the key concepts of constructivist psychology as a theoretical model and interpretative phenomenological analysis (IPA) as a theoretical concept and qualitative analysis tool. Firstly, some facts in relation to ovarian cancer will be detailed, to place the forthcoming IPA analysis and discussion of women's experiences in context.

2.10.1. Ovarian cancer some facts

Ovarian cancer is difficult to diagnose with vague, non-specific, unexplained abdominal symptoms (NICE, 2005, pg 13) such as:-

- bloating
- constipation
- abdominal pain
- back pain
- urinary symptoms

Recent statistics report an incidence of ovarian cancer of 6,615 cases per year in England and Wales, which resulted in approximately 4,447 deaths in 2005, an incidence of 17.2, or 1 in 48 women (CancerStats, 2008), the highest mortality of any gynaecological cancer.

The earlier ovarian cancer is diagnosed, the better the prognosis (i.e. Elit et al, 2004). Women with ovarian cancer may not present to their doctor until the disease is at an advanced stage. Neal et al (2000), suggests that such delays may be related to faulty cognitive construction and decision-making in some of the women. However, possibly due to the difficulties of diagnosing ovarian cancer (NICE, 2005), Kirwan (2002) reported that in their study some of the women had attended several times prior to diagnosis, this may still not have been soon enough. It is important to understand how individual conceptions of 'reality' are experienced and interpreted in order to contextualise their experience. Within the behavioural sciences literature, constructivist psychology is a theoretical framework that may be used to understand individual cognitions in this process.

2.10.2. Constructivist psychology

Constructivist psychology examines how individuals construct and perceive their interpreted reality and create systems of understanding in order to negotiate everyday life. Personal interactions and communication between patients and health professionals is a major theme throughout this thesis. Therefore how each individual constructs and perceives their own reality in relation to their diagnosis and disease trajectory is a crucial issue. Constructivist psychology theorise on how human beings create systems in an attempt to meaningfully understand their world and experiences (Neimeyer and Raskin, 2001, Botella 1995, Mahoney 1998). The linguistic communications and interactions people initiate and become engaged in, are interpreted and constructed into individual realities. Individual experiences may be perceived differently, dependent on internal and external factors.

Constructivists share a common belief that none of the many ways of understanding that people have developed, provide a truly objective view of the world, personal interpretations are constructed through individual and subjective experiences (Raskin, 2001). Constructivist theories in psychology have grown immensely in quality and influence over the past fifty years, originating in a variety of theoretical and research areas. Raskin (2001) suggests that as the 21st century began constructivist psychologies were ready to influence the broader discipline of psychology. Sexton (1997) in his historical analysis of the changing nature of *knowing* divides human history into three distinct eras: –

- Pre modern - from sixth century B.C.
- Modern - through the Middle Ages
- Post modern - present era

Each of these eras shaped a particular ontological perspective that influenced how people dealt with events, problems and generally attempted to explain life and its problems. The pre modern (from sixth century BC to Middle Ages) emphasised dualism, idealism and rationalism. The role of faith and religion was the central force that ruled or dictated thought in this era. Then by comparison, the modern era, through the Renaissance to the end of the seventeenth century, stressed empiricism, logical positivism, scientific methodology and the identification of objective truths. A major consequence of the modern era was the solidification of scientific and professional knowledge, as a realistic and true source of understanding within society. Sexton (1997) suggests that scientific knowledge was seen to act as a mirror image of objective reality. The post-modern present era, Sexton labels as post modern/constructivist. This Sexton depicts as *emphasising* the creation, rather than the *discovery* of personal and social realities. Constructivist theorists are concerned with *how* people know, as well as *what* they know. This compares with modernism, truths independent of subjective bias are revealed to neutral scientists, with post modernism and constructivism highlighting human participation in the construction of knowledge. Chiarri and Nuzzo (1996), argue that all constructivist psychology attempts to conceptually bridge realist and idealist approaches to knowledge. Whilst a *realist* stance suggests, material objects exist externally and independently of our sense experience, the *idealism* stance would argue that no such material objects or external realities exist, apart from individual knowledge or consciousness of them (Chiarri and Nuzzo 1996).

Philosophising within the realism/idealism dichotomy, Chiarri and Nuzzo (1996), establish two broad categories of constructivism, epistemological and hermeneutic and suggest that constructivism can be part of either category. An epistemological constructivist would view knowledge as a compilation of human made constructions. Individuals do not know if their constructions correspond to an independent reality, but they do know if their constructions work well for them. A hermeneutic constructivist approach highlights knowledge as a product of the linguistic activity of a community of observers. In this way, numerous knowledge systems exist amongst the multiplicity of groups that actively negotiate and communicate this knowledge and content. In hermeneutic approaches to constructivism, language, discourse and communication are pivotal in an understanding of how knowledge systems are developed and maintained. Although the historical backgrounds differ, the two approaches share the view that knowledge (and truth) as interpretation is contextually verifiable, linguistically generated and socially negotiated (Chiarri and Nuzzo 1996).

Kelly (1955; 1991) pioneered Personal Construct Psychology (PCP) or Personal Construct Theory (PCT), proposing that people organise their experiences by developing bipolar dimensions of meaning or personal constructs. These hierarchically and interrelated constructs are then used to anticipate and predict how the world and its inhabitants may behave and react. By inventing dimensions of meaning that account for events, people accumulate psychological experience. Constructs are tested, by 'tracking' how life circumstances are predicted and by revision if judged deficient. PCP uses the metaphor of the knowing individual as a personal scientist, who continually tests their constructions. Kelly (1991) expands this concept to include constructive alternativism, which creates infinite possibilities for conceptualising events. If previous sets of constructions prove unsatisfying, individuals are free to create and develop entirely new dimensions of meaning. Personal construct theorists use Kelly's concept of 'hostility' to describe those who maintain faulty constructions in the face of invalidating evidence. The formation of close relationships is based upon the PCP definition of *sociality,* which requires people to interpret the constructs of others, with whom they wish to interact. When effective *sociality* leads to *role relationships,* in which individuals are able to understand each other intimately (Kelly, 1955). Individuals within Kelly's paradigm are active creators of their own personal meanings (Butt, 2000, Neimeyer and Raskin, 2001) and use the 'person as scientist' metaphor, as a cognitive behavioural emphasis on rationally examining experience as a basis for improving knowledge.

Von Glaserfeld's (1995), radical constructivism emphasises the ability of individuals to use the interpretation and understanding they create to help them navigate life, regardless of whether or not such understandings match an external reality. Von Glaserfeld suggests that human perception is adaptive, evolving to help people survive and sees human cognition as a closed system. He states people are capable of knowing only when their constructions of events fail, but are never capable of knowing truth in any kind of direct, objective manner. Von Glaserfeld relies heavily on the writings of Piaget in advancing the ideas of cognitive adaptation (1984, 1995), arguing that assimilation and accommodation are basically constructivist concepts. Assimilation is constructivist in that it entails adapting information for individual experiential understanding. This relates with Piagetian schema theory (Paiget, 1965) as von Glaserfeld views mental schemas as involving assimilation. The first part of the schema involves recognising (or representing to oneself) a particular circumstance (i.e. worrying signs and symptoms). The second part involves taking an action associated with that circumstance (i.e. apprehensively visiting a doctor). The third involves an expectation that the action taken will produce a predicted result (i.e. hoping the diagnosis is nothing to worry about). Rather than describing accommodation as an alteration of an individual's schema to more accurately reflect the world, von Glaserfeld (1995) discusses accommodation as a process determined by an individual's unobservable expectations. It is the failure of internalised mental schemes, rather than the direct impact of external reality, that leads to accommodation.

Von Glaserfeld (1995) suggests individuals operate in their own private, self constructed worlds. Language and social interaction allow for interpersonal communication, but do not permit an individual to escape from encased isolation, as a *knowing being*. Leading on from this, Loria (1995) suggests all speakers use private languages. Although specific words may be familiar, personal histories influence that way people create unique meanings. And the way people (patients) interpret these words and meanings (palliative, incurable, recurrence) is crucial in the subsequent interactions, the so called 'communal choreography' of Efran and Fauber (1995), and in the construction of individual lives. The 'communal choreography' instigated via language, forms the characteristics of the 'social dance' that people use to choreograph their lives is central to the radical constructivist views of Maturana (1988).

Maturana and Varela (1992) describe the concept of structure determinism; all changes in an organism (individual) are determined by their structure. Similar to von Glaserfeld, Maturana and Varela view living systems as cognitively closed. That is as individual living systems who believe they are mapping out external worlds, but who are experiencing and processing their own structurally determined responses. Features of the environment, external or internal become important when they 'trigger' changes in the structural dynamics. However, Maturana (1988) suggests that, the environment never directly 'instructs' the system how to behave. Depending on variances and differences of individuality, organisms remain uniquely sensitive or robustly unresponsive to types of environmental stimulation.

Maturana (1988) views the organisms existence consisting of a continuum of structural change in relation to the medium (society/environment) in which it exists. This 'history of accommodations' he views as 'natural drift', which is without meaning or intention, until a 'disintegrating' event occurs. An event that threatens or actually destroys the organisms' autopoietic (self-creating and self-sustaining) structure. Central to this concept is Manturana's and Varela's (1992) 'structural coupling' (1992), wherein two basic systems recurrently interact in such a way as to form a unity of their own, a 'second order unity'. At a societal level, couples group to form communities which, in turn enhance their own survival, referred to as 'third order couplings'. Within this grouping, the social phenomena develop within a linguistic domain, as human beings are relatively unique in their ability to create new languages (and ultimately new meaning and interpretation). Using this language, individuals are able to evaluate accumulate knowledge.

Von Glaserfeld (1995), Kelly (1991) and Muturana (1988) all outline approaches in which people are considered self organising systems whose ability to construe the world is determined by their psychological structures (Kenny and Gardener, 1988), with each individual further creating the world by living it. For Maturana, the truth one discovers, vary in accordance with the 'position' of the observer. Rather than viewing individuals as trapped in a set of private meanings expressed through language, Maturana emphasises the role of third order couplings, as these produce social unities. He sees these systems or societies producing cohesion with interacting groups, supporting and sustaining each other, creating specific realities.

Hruby (2001), from a social constructionist perspective, suggests throughout life individuals construct reality depending on the various frames, context and social surroundings which form their interpersonal boundaries. Gergen (1991) supporting the same theoretical framework, proposes that personality is a socially constructed phenomenon, viewing each individual as being a 'multiphrenic self', socially constituted within boundaries of culture, context and language. Burr (1995) expands on this and talks about 'personhood' becoming a matter of how people are talked about, the social practices they engage in and the particular relationships they become involved with. These multitudes of identities are negotiated and defined within specific interpersonal relationships and social contexts.

For social constructionists, language is a crucial determinant in how people explain their world and the nature of experiences. Gergen (1991) discusses the role of language culturally in power relationships, and within the frame of this thesis, language is also critical in establishing how information is relayed, as a two way process between individuals (patients, health professionals, relatives, partners, researchers). Information is powerful, the level, form and terminology used impact on individual interpretation and prioritisation of reality. These 'social negotiations' contrast to the more isolated forms of 'personal knowing' characterised by von Glaserfeld (1995) and Kelly (1991). Social constructionism focuses on relationships and joint actions, and Shotter (1993) emphasises that it is the co-operation and execution of shared meaning that occurs when individuals interact, that is crucial.

The theoretical perspective of constructivist psychology is a useful means of understanding individual perspectives. An analytic technique well suited to this framework is interpretative phenomenological analysis. This technique is concerned with lived experiences and the meanings individuals attribute to events and occurrences in their lives.

2.10.3. Interpretative phenomenological analysis

Whilst many qualitative methods are concerned with accessing lived experience, they approach and deliver many differing aspects of this lived experience (Willig, 2001) and challenge the possibility of objective knowledge, essentialist subjectivity and progressive ideology (Madill et al, 2000). IPA finds much of its theoretical basis in phenomenology, which originated in Husserl's (1925) attempt to construct a philosophical science of consciousness. The second IPA influence is that of hermeneutics, the theory of interpretation and the third influence is that of symbolic interactionism (SI), which emphasises the importance of individual meaning. SI theory suggests human beings are not merely passive beings of objective reality; they interpret life experiences into understandable actions, to make sense and negotiate their world (Brocki and Wearden, 2006). IPA focuses on the processes and reasoning behind how and why individuals arrive at these decisions and the processes individuals negotiate to reach decisions (Smith and Walsh, 1997).

Reid et al (2005) suggests that IPA's increasing popularity within health psychology derives from its ability to make substantial contributions to biopsychosocial perspectives in health. As with positive psychology (Seligman and Csikszentmihalyi, 2000), IPA also provides an opportunity to explore wellness and quality of life issues. In addition, within health care the opinions of service users are encouraged and IPA is useful in this process. As Reid et al (2005, p.23) suggest:

> "IPA is particularly suited to researching in unexplored territory, where a theoretical pretext may be lacking. Bypassing the closed systems of borrowed hypotheses and theories, it can instead provide meaningful and unexpected analysis of psychosocial issues."

The rise of qualitative research in psychology

Fischer (2006, p 24) notes that in England, qualitative and discourse analysis has a longer record of use than in America, especially in psychology, and certainly discourse analysis, grounded theory and IPA do appear prominent in United Kingdom (UK) psychological theory and research (Henwood and Pigeon, 1992). For example, discourse analysis became popular in the U.K. during the 1980's; particularly within critical and feminist psychology and IPA has been gaining popularity within health and clinical psychology since its development by Smith (1996a).

Ashworth (2003) discusses the variety of approaches taken in psychological method, with the initial striving for 'psychology as a science' in the latter part of the nineteenth century. At this point, experimental psychology was defined as the science of experience and replicated as far as possible the physical sciences. The aim being that by studying the inner world of experience, psychology could develop a scientific understanding, based on quantitative and experimental methodology. Ashworth (2003) discusses that the methodological stance taken for granted within the natural sciences is positivism, supporting the central idea that only events that can be observed and only propositions that can be tested, have a claim to *truth*. For example,

- Realism - there is a single, unitary real world within which events of interest to psychology take place.
- The individual is part of this real world, and so such processes such as memory, emotion and thoughts are events in the real world with definite enduring characteristics.
- The purpose of science is to set up experimental situations in which characteristics can reveal themselves.

Ashworth (2003) suggests by rejecting positivism, qualitative psychology refutes the concept of an unequivocal real world and suggests instead the idea that people formulate their own reality. In this way theoretical viewpoints are 'oriented' to personal interpretations. Rather than the world being seen as a unitary, single state, it is different worlds, lived and experienced by individuals, in their own unique way.

Husserl's (1925) core philosophy was based on the rejection of the previously held supposition that there is 'something *behind, underlying* or *more fundamental* than experience'. Instead, Husserl stated what *is*, should be taken as reality, and any investigation should focus on what individuals experience. Thus, experience should be a system of interrelated meanings that together form what individuals understand as 'life world'. Taken in this context, a natural scientific approach is thus inappropriate. Human meaning is viewed as the key to lived experience and the result of causal variables. For example, rain may have different meaning to the individual experiencing it, if on a picnic, or a farmer with parched crops.

IPA has been developed with a new and idiosyncratic approach to undertaking qualitative research in psychology (Brocki and Wearden, 2006; Smith, 1996a) and has generated considerable interest and debate amongst psychologists (Chapman and Smith, 2002). The origins of IPA are firmly rooted in phenomenology (Giorgi 1995) and symbolic interactionism (Denzin, 1995) and have been refined as a distinctive method of conducting experimental research in psychology, with an emphasis on *quality* and not *quantity* of data. The importance of language and qualitative analysis is similar to that of discourse analysis (Potter et al 1987), but the important distinction is that IPA highlights and emphasises the importance of cognition in the interpretation and understanding of the data (Chapman and Smith, 2002). Discourse analysis views individual interactive tasks, together with linguistic communication and construction as the theoretical framework in which the data is analysed and explained. IPA in comparison moves away from this didactic and involves understanding cognitive interpretation, rather than reliance on externalised verbal reports.

The study of individual human experience from a psychological perspective is suited to qualitative research, with the interview as an effective means of data acquisition. DiCicco-Bloom and Crabtree (2006), view the interview as a technique to reconstruct perceptions of events and personal experiences.

The analysis techniques used with qualitative data are varied and will depend to some extent on the theoretical framework applied. For example, thematic analysis focuses on the coding of qualitative data, producing clusters of text with similar meaning, searching for a common theme to capture the fundamental phenomenon under investigation (Braun and Clarke, 2006). It differs from discursive methods that tend to focus on the minutiae of the text. In this way, the details of the text explicate ways in which the phenomenon under study is highlighted, through the use of linguistic resources such as the study of speech interaction and applied discourse theory (Wetherell, 1994). The fundamental analytical principles in any content analysis can vary and include structured approaches for example within case data, as discussed by Miles and Huberman (1984). Pettigrew (1988) suggests a real risk of 'death by data asphyxiation' with case data, as the method involves the use of large volumes of data. The concept of searching for in-group similarities and differences, core concepts and cross-case searching with interviews, questionnaires and observational studies, are methodological perspectives to achieve accuracy and reliability. Their focus is on incidents and occurrences and whilst a useful tool within for example grounded theory, they are not the method of choice when attempting to determine the phenomenological experiential accounts of individual case studies, where personal psychological descriptions are under scrutiny.

In phenomenology, the individual is the 'conscious agent' whose experience must be studied from the 'first person perspective', they are the only people who can creatively and with certainty, interpret their actual 'life world' experiences. It is this crucial commitment to cognition in IPA that bridges the interpretive gap, other methods fail to produce. IPA produces richer and more perceptive data via this experiential method. Within IPA, the researcher must recognise that individuals are complex. Certain individuals have difficulty in expressing and verbalising their feelings, especially during times of stress, for example following diagnosis of terminal disease, or prior to physical investigation of genetic or serious illness. Many emotional issues could be involved and cognitive prioritisations will vary amongst individuals. The IPA researcher must interpret what the individual verbalises and the *meaning* behind what is said. This involves being aware of and considering individual and emotional and mental factors involved.

This emphasis on 'sense making' by both researcher and participant suggest that cognition is the central framework and Smith (2004) discusses the theoretical importance of this, in contemporary psychological thinking. Connecting similarities are viewed with a centralised concern of the 'mental process', which Smith (2003), suggests structure the link between IPA and social cognitive psychological theory (Fiske and Taylor, 1991). Smith (2004) suggests that whereas there are definite similarities within the theoretical juncture, it is in the methodology of IPA that diverges from contemporary thinking. IPA uses in-depth, personal qualitative analysis and Smith et al (1999), explicitly state that it is not appropriate or indeed necessary to provide an absolute methodology for IPA. The basic process in IPA involves traversing from descriptive to interpretative; it does not seek to claim objectivity, as other methodologies may do via detailed formulaic measures. For example, Senior et al (2002), using IPA, initially categorised individual scripts into broad themes, moving on to develop more individualised specific themes. This initial familiarisation stage is approached in different ways by different researchers and Collins and Nicholson (2002) undertook analysis by recording anything in the transcript that related to previous literature and theory on the research topic. This is the point where IPA distances itself from previous theories, with Smith et al (1999), emphasising that at this stage, importance should be focussed on, "Themes and connections available within the text, rather than attempting to find instances that would fit a particular pre-existing theoretical, viewpoint" (p 231).

Another major difference with the IPA approach is demonstrated in the sampling and the participant inclusion strategy. The emphasis in IPA is on *quality* and not *quantity* of participant data. In a literature review of IPA undertaken by Brocki and Wearden (2005), numbers of participant interviews varied from 1 (Robson, 2002) to 30 (Collins and Nicolson, 2002). Smith and Osborn (2003), argue the sample size depends on a number of factors and emphasise that there is no 'right' sample size (p.54). This is explained in that as IPA is an idiographic, individualised method, with small sample sizes normal as opposed to exceptional. Small sample sizes are advocated as important, in order to avoid neglecting subtle meanings or nuances. For example, a deep meaningful analysis, with insightful interpretation can be obtained via intense concentration on a small data set (Smith, 1996a). Smith (2004) and Reid et al (2005), suggest that published studies utilising IPA have resulted in an emerging consensus towards the value of smaller sample sizes in qualitative research.

IPA sampling tends to be purposive and broadly homogenous, as it is suggested that a small sample size can provide a sufficient perspective, given adequate contextualisation (Smith and Osborn, 2003). In this respect, IPA differs from other methodologies, such as grounded theory, as in IPA the aim is to select participants in order to *illuminate* a particular research question, and to develop a full and interesting interpretation of the data. Grounded theory, on the other hand, uses theoretical sampling, which aims to collect data, conduct analysis and continue collecting data, mindful of prior analysis, until no new themes emerge. Thus, whilst grounded theory may seek to establish claims for the broader population, IPA research studies focus on examining divergence and convergence in smaller samples (Brocki and Wearden, 2006, p 95).

Therefore IPA may be viewed as an inductive approach. It does not aim to test any hypothesis and prior assumptions are avoided, rather than adopted (Reid et al, 2005). Participants are seen as the 'expert' of their own experiences, offering an interpretation of their cognitions through their interpretation and telling of their experiences or 'stories'. IPA provides the research psychologist with the opportunity to engage with a research question at the idiographic level, unlike most traditional psychology. The participants 'lived reality' is linked to an interpretative process of analysis, with the researcher becoming explicitly engaged in the process of cognitive interpretation of individual experience.

Collecting data for IPA involves detailed analysis of individual case studies. The objective is for the researcher to analyse in detail, how the participants perceive and make sense of their experiences. This may be collected in a variety of ways such as personal diaries and accounts, but the method of choice for IPA is the semi-structured interview (Smith and Walsh, 1997). This enables researcher and participant to participate in a discourse, with questions on areas of interest. However, the interview may deviate considerably from the original planned areas of discussion as IPA is flexible in approach and accommodates divergent theoretical transgression, in order to enable cognitive insight and phenomenological interpretation.

Interpretative Phenomenological Analysis (IPA) highlights the importance of cognition in the interpretation of linguistic communication. Through a specific didactic analysis, IPA enables the crucial understanding of the reasoning supporting participant verbal statements in face-to-face interviews and subsequent analysis. Interpretative Phenomenological Analysis (IPA) emphasises that research is a dynamic process involving both researcher and participant (Smith, 1996a; Brocki and Wearden, 2006). To obtain an active understanding of the psychological and social constructions, the researcher must be aware of their own conceptions, as well as those of the participant. In this way, Smith and Walsh (1997), suggest research takes on 'a two stage interpretation process, or double hermeneutic. He explains this by discussing the participant making sense of their world and the researcher attempting to make sense of the participant interpreting their 'world'. Smith (1997) suggests that IPA has an intellectual link with hermeneutics, with interpretation and understanding from both researcher and participant perspectives being crucial.

Smith (1996a) suggests that IPA is an important tool when utilised in health psychology as it triangulates individual physical condition, linguistic and cognitive responses. Smith suggests that in utilising IPA, a body of knowledge is being created which provides enhanced specificity on understanding the experience of health and illness. IPA research in diverse health areas has demonstrated that individual interpretation is crucial in understanding and the subsequent development of coping mechanisms, for example in attitudes toward sexual behaviour (Smith et al, 1997) and experience of chronic back pain (Smith and Osborn, 1997). IPA has also been used in the area of genetics (Chapman and Smith, 2002) and risk status and decision making (Senior et al, 2002). Such areas are complex and appropriate for IPA to explore, because IPA allows for the individual and personal expression of decision making, in emotionally intricate areas (Harper and Clarke, 1997; Harper et al, 2000). Health and possible future issues can be difficult to negotiate, for example results from genetic testing may be the decisive factor in a couple considering having children. To understand cognitive factors, interpretations and decision-making in such multifaceted situations, the researcher has to interpret and understand how a participant constructs their reality logistically and emotionally rationalises events. Each participant arrives with their own agenda including a personally construed set of beliefs, knowledge base and health issue, such as genetic inheritance. Each individual has their own cognitive interpretations, needs and goals, which Chapman and Smith (2002), suggest can be effectively captured, utilising the strengths of IPA to access internalised complex and often contradictory individual perspectives.

Smith (1996a) highlights a gap in individual *perception* of their disease or illness and their *understanding* of their disease; IPA provides a means of bridging this gap. For example, two patients diagnosed with the same disease may be interviewed and express entirely different subjective responses to diagnosis, prognosis and living with the disease. Whilst diagnosis, treatment and physical responses to the disease may be similar in both patients, IPA provides a means of exploring individual divergent cognitive interpretations. Smith (1996a) believes IPA has major implications for qualitative health psychology research. Utilising IPA as an analysis tool provides an understanding of cognitive interpretations, with its flexible approach to theoretical 'transgression' and phenomenological interpretation.

2.11. Chapter summary

This literature review has undertaken a qualitative critical appraisal via a narrative review of the prior literature on the experiences of women with ovarian cancer. In addition, a brief summary of ovarian cancer facts has been provided for context and the importance of social constructivism in psychology, as a theoretical concept in understanding interpretation and meaning discussed. The theoretical basis and foundations of IPA as a means of interpretation has been explored. The literature review has provided the context for the research presented in this thesis.

CHAPTER THREE

Methodology

3. Introduction

This chapter will detail the research methodology and also discuss some of the pertinent methodological issues.

Firstly the methodology of the research pilot phase 1 and main research phase 2 will be presented. This will include a rationale for the analysis framework chosen for each phase. Following this some additional methodological considerations will be discussed. This will include other qualitative methodologies considered for the research. By presenting the sections in this order it is hoped to provide clarity and provide as Yin (1994) defines as required, a clear rationale for the analytic strategy adopted in the research.

Aims

- To understand the issues involved in the experience of ovarian cancer.
- To gain insight into the experiences, beliefs and psychological constructs of women with ovarian cancer.

3.1. Research phases

The research was undertaken in two distinct phases and Table 3.1 provides an overview of the research strategy. Following this the methodology and rationale for each phase is detailed separately for each phase.

Table 3.1: Phases of the research

Phase 1- Pilot			
1. Women selected from Trust database 2. Letter, information sheet consent and questionnaire to 28 women	15 agreed to participate	15 questionnaires returned and 13 of the women agreed to a face to face interview session is tape recorded	*Data analysis* Thematic Analysis
Phase 2- Main study			
1. Women selected from trust database 2. Letter, information sheet and consent to 11 women	5 women agreed to participate	5 women interviewed session is tape recorded	*Data analysis* Interpretative Phenomenological Analysis (IPA)

3.2. Phase one pilot

Rationale

- To understand the issues involved in the experience of ovarian cancer.

Overview

1. Prior to interview women were mailed an initial questionnaire on background and signs and symptoms, preliminarily used to evaluate similarities and differences in recollections of signs and symptoms. The prior to interview questionnaire provided information that could be tabulated and facilitate the qualitative interview to proceed, discussing relevant issues, without the interview potentially being too time consuming or difficult for the participant (BPS, 2004; APA, 2002; Mertens, 1998).

Whilst not necessarily congruent with qualitative research, as the narrative review detailed in chapter two, many variants have been used to obtain data with a qualitative element (i.e. Ziebland et al, 2006; Akyuz, 2008; Power et al, 2008; Wray et al, 2007; Swenson et al, 2003,). Silverman (2006, 2004); Pope and Mays (1995) and Mason (1996) provide a comprehensive discussion of various methods. Furthermore, Coolican (2009), outlines that the methods that "could count as qualitative, include open-ended questionnaires and unstructured and semi-structured interviews" (p.230).

2. In-depth semi-structured interview focused on issues of importance to each woman.

3.2.1. Ethics

Ethical approval was obtained from South Cheshire and Liverpool LREC for research phase 1 in 2002 (appendix 3). South Cheshire ethical committee requested practice is for information and consent letters to be on Trust headed paper to prove the authenticity of the research. This procedure was followed (appendix 4).

Women approached to participate in the research were provided with a written information sheet (appendices 5 and 6), explaining why the research was being conducted and that interview information was for research purposes only and a consent form, which was to be signed if they agreed to participate in the research (BPS, 2004). This was signed and dated by both the researcher and the participant. A copy of the consent form was retained in the case-notes, one was retained by the researcher and one returned to the patient. All data obtained was anonymised and stored in a locked cabinet.

Participants were asked whether they had objections to the interviews being tape recorded and none objected. They were also reminded that they were under no obligation to disclose anything if they felt uncomfortable, and also that the tape recorder could be turned off at any point, if they wished. The original interview tapes were destroyed once the transcripts had been transcribed, validated and analysed.

3.2.2. Population demographics where research took place and transferability considerations

The research was conducted in an NHS Trust hospital in Cheshire. The sampling was purposive, in that any woman who met the inclusion criteria at the time of research phase 1 or 2 was invited to participate. All of the women who agreed to participate were from North Wales, Wirral, Ellesmere Port, and Chester, all areas covered by the hospital. The population of Cheshire is 673,781 and North Wales population is 670,800 (Census, 2001), with lower representation of black and ethnic minorities (BME) at 2% in Cheshire and 1.2% in North Wales, than BMEs in the North West (6%) and England and Wales (9%) (Census, 2001). No women from BME groups participated in the research. There was a mixture of middle and working class participants in the research sample, from both urban and rural populations.

3.2.3. Participants

Sampling considerations

Selection of cases is a crucial issue (Eisenhardt, 1989; Silverman, 2006; Miles and Huberman, 1994) and for phase 1, purposive sampling was used. The aim was to obtain a homogeneous group of women with ovarian cancer, at a similar disease stage to explore experiences. The rational of screening all cases of women diagnosed with ovarian cancer and then inviting all women who fitted the inclusion criteria (see inclusion criteria below), was to obtain a sample of women at the same stage disease trajectory, who had undergone surgery and chemotherapy and thus experienced similar disease and treatment journeys.

Replicability and generalisability (Eisenhardt, 1989; Miles and Huberman, 1994) were also serious considerations. Miles and Huberman (1994, p. 173) state, "we would like to know something about the relevance or applicability of our findings to other similar settings". However, Denzin (1995, 2001) suggests that generalisability is inappropriate for qualitative research. The research aimed to qualitatively evaluate women's experience with a particular illness, from a specific area of the UK at a specific time point, it was anticipated that the results, whilst providing valuable information of possible use to other researchers, would not necessarily be generalisable to another population, region or culture.

Sample size provided some limitations due to the incidence rate of the disease, inclusion criteria and willingness of women to participate. Women with other cancers could have been included in the research to increase participant numbers. However, the research aim was to explore in depth, the experiences of a particular group of women with ovarian cancer, at a micro-level, not to generalise necessarily to other groups (Smith, 1996; Smith and Eatough, 2006, 1999). Furthermore, there is a growing consensus in qualitative research towards smaller sample sizes (Smith, 2004).

3.2.4. Inclusion criteria

In phase 1, potential participants were selected from the hospital database by the researcher. Between January and December, 2004, women (N=34) coded on the database with a diagnosis of ovarian cancer, who had completed surgery and had undergone chemotherapy were invited to participate in the research. In addition, in order to ensure it was appropriate to approach potential participants, the opinion of the Oncology specialist nurse was sought and women were excluded if the nurse felt it would present any issues for the women. Six women were excluded (psychiatric history and attempted suicide - 1, clinical depression -1, other major disease -4 (of the 4 excluded with major disease, 2 were cardiac and 2 respiratory). Following exclusion criteria being applied, 6 women were excluded and the 28 remaining women were invited to participate. Criteria for inclusion are detailed in table 3.2. By having homogenous cases, it was hoped to establish patterns of similarities and differences between the women during analysis.

Table 3.2: Phase 1 Inclusion, exclusion, selection and screening criteria for participant selection

Inclusion Criteria	**Exclusion Criteria**
Diagnosis of ovarian cancer Undergone surgery Recently (within 3 months) completed chemotherapy Women of any age	Any other major disease Mental disorders Inoperable ovarian disease
Selection	**Screening**
Selection process identified through patient health records	1. Hospital database of patient health records 2. Discussion with Oncology specialist nurse.

3.2.5. Participant information

Tables 3.3 and 3.4 detail the phase 1 process and participant information.

Table 3.3: Phase 1 process

Phase 1- Pilot			
1. Women selected from Trust database 2. Letter, consent and questionnaire sent to 28 women	15 agreed to participate	15 questionnaires returned and 13 of the women agreed to a face to face interview session is tape recorded	*Data analysis* Thematic Analysis

Table 3.4: Phase 1 participant information

Participant	Occupation	Marital status	Stage of disease at diagnosis	age
1	Healthworker Manager	Married	Early	52
2	Taxi driver	Divorced living with new partner	Advanced	44
3	Housewife Pregnant	Married	Advanced	43
4	Retired Teacher	Married	Advanced	68
5	Retired Housewife	Married	Advanced	70
6	Teacher	Married	Advanced	52
7	Retired Head Teacher	Married	Advanced	68
8	Retired Teacher	Widowed	Early	70
9	Retired Shop assistant	Married	Early	67
10	Retired Teacher	Married	Advanced	69
11	Retired PA in Industry	Married	Early	71
12	Clerical	Married	Advanced	58
13	Retired Clerical	Married	Early	69

3.2.6. Prior to interview questionnaire

Questionnaire distribution

An invitation to participate, consent form and pre-interview questionnaire was sent out to all women (N=28) who met the inclusion criteria and were not excluded by the exclusion criteria. Of the 28 women invited to participate, 15 consented and returned questionnaires, of which 13 agreed to face to face interviews. The 2 other women completed questionnaires, but declined to engage in a face to face interview, undergoing instead a telephone interview.

As the researcher, I felt it important to allow the two women to speak to me by telephone, as they had indicated their desire to do this on the consent form. I recorded a reflection in my diary at the time that "I need to provide this opportunity". The two women were excluded from the final analysis, as the data was considered incomplete, in comparison with the face to face interview data. Pre-interview questionnaires were distributed between January and December, 2004. Due to the clinical condition of the disease and possible emotional factors, it was decided not to follow up the 13 (N=13/28) non-responders (BPS, 2004; APA, 2002).

3.2.7. Prior to interview questionnaire content

The Questionnaire (Appendix 7) for self-completion was designed with specific open-ended questions to obtain the women's perceptions of their symptoms and their knowledge of ovarian cancer. The questions were related to physical signs and symptoms prior to diagnosis of ovarian cancer and the demographic information of date of birth, name and address (for further contact if participant agreed) and occupation. Demographic questions were optional. Information provided to the participant stated that all data was for the purpose of research only and all information anonymised (BPS, 2004; APA, 2002, ethics principles, Caldicott principles, DOH, 1997 and the Data Protection Act (1998). All participants completed these details. This data gave additional information regarding class status, occupation and if working or retired. The information provided useful contextual information and gave some insight into the woman's ability to understand, communicate, and search for further information regarding the disease. A final question asked women if they were willing to participate in a face to face interview.

DeVaus (2004) discusses the importance of distinguishing between five distinct types of question content, behaviour, beliefs, knowledge, attitudes and attributes to determine the correct responses from the participants. As the questionnaire was aimed at obtaining beliefs and attitudes of the women and also to ascertain the level of knowledge they held regarding ovarian cancer, the questions were carefully structured to probe such responses. All questions were open ended, as it was intended to allow the women to highlight and prioritise the areas that they viewed as important throughout their diagnosis and treatment journey. This information was used as a baseline for the in-depth interview. To ensure validity and reliability (Meyrick, 2006; Ashworth, 2003; Smith, 1995), the questionnaire was piloted on a gynaecology ward with 10 patients. This indicated two minor revisions, the re-ordering of two questions and re-wording of one question (Foddy, 1993; Yin, 1994).

Questionnaire responses were carefully evaluated and formed a framework for expansion and discussion during the face to face interview. The areas or questions the women had identified as important on the questionnaire, by giving fuller, more expansive answers were utilised as prompts during interview to ascertain why and how these were seen as important issues. Also the minimally responsive questions were introduced to discover why these were considered 'unimportant' or insignificant (Crossley, 2003). This proved effective, as it elucidated several new areas of discussion, which the women had previously not considered.

3.2.8. Face to face interviews

Procedure

Interviews took place in the hospital, in a quiet room or participant home, between January and December, 2004, within one month of the participant agreeing to interview. The duration of the interviews varied from one to one and a half hours, and were semi-structured (Appendix 8). Following each interview, I made summary interview notes and also kept self-reflective notes, which referred to any relevant issues such as my reflections and the interview process.

Interview process

Certain areas of questioning were targeted throughout the interview and leading questions specifically introduced the areas. Once the subject area had been introduced, the participant was encouraged to discuss the topic with their own prioritisations and interpretations, with prompts from myself as the researcher to expand or clarify issues as and when they arose. Throughout the interview, the participant was encouraged to express their own opinions and direct the discussion.

Following interview, I ensured participants were aware of contacts where they could obtain further information and support should they feel this was necessary. For example, support within the local Trust was the oncology specialist nurse, a chemotherapy support unit nearby and various web-sites which could be accessed.

3.2.9. Interview analysis

Interviews were tape recorded and transcribed verbatim for analysis. Pilot data was analysed via thematic analysis (TA) at the end of the interview period (Braun and Clarke, 2006). Analysis was not undertaken until the final participant had been interviewed, as in the pilot phase 1, I did not in any way wish to influence ongoing interviews, merely gather the *breadth* of the experiences of the women. Therefore, unlike grounded theory (Strauss and Corbin, 1998; Glaser and Strauss, 1965) data was not collected, until saturation occurred and no new themes emerged.

Following data transcription, the data was analysed in six stages:

1. Read through each transcript
2. Code generate
2. Search for themes across and within transcripts
3. Review possible themes
4. Define themes
6. Name themes

I read through the transcripts several times, to become familiar with the data and then started to generate initial data codes. In particular, the initial framework of patterns of connected experiences, were listed, with data pertinent to these examples highlighted and grouped i.e. responses to GP interactions or positive and negative hospital experiences. The next stage was to proceed to search for themes and sub-themes, across and within the transcripts. Following this, identified themes were reviewed, defined and finally named.

Validation of the analysis was provided by frequent reading of transcripts and analysis by both researcher and supervisor. Each part of the process was overseen and supported by my supervisor and other experienced psychologists consulted as necessary on methodological queries.

Data was analysed using thematic analysis (TA), a widely used qualitative analysis technique in psychology (Braun and Clarke, 2006; Boyatzis, 1998), this produced themes regarding the women's perceptions of their disease. The advantages of thematic analysis in pilot phase 1, related to its flexibility and its ability to highlight similarities and differences across the data set. As understanding of the breadth of such issues was all that was required in the pilot phase (the main research phase, would incorporate a deeper level of psychological analysis). The process of thematic analysis should be made explicit in the methodology, as themes represent a patterned response or meaning within the data set. Braun and Clarke (2006) provide criteria for undertaking a good quality thematic analysis. To ensure research validity was enhanced, the following quality standards that reflect Braun and Clarkes (2006) criteria for quality thematic analysis were implemented in research phase 1:

Transcription - The data was transcribed to an appropriate level of detail, and the transcripts have checked against the tapes for accuracy.

Coding - Each data item was given equal attention in the coding process. Themes were not generated from a few examples, the coding process was thorough, inclusive and comprehensive. All relevant extracts for each theme were collated. Themes were checked against each other and against the original data. Themes were internally coherent, consistent, and distinctive.

Analysis - Data were analysed and interpreted, rather than just described. Analysis and data mirrored each other. Analysis developed a story about the data and topic. A balance between analytic narrative and illustrative extracts were provided.

Writing - The assumptions and approach to thematic analysis were clearly outlined. There was a good fit between the method and analysis. The language and concepts were consistent with the epistemological position of the analysis.

Overall - All analysis phases had the time to be adequately conducted. As a researcher, I recognised that I was active in the research process and kept a reflective diary of my thoughts, feelings and recollections.

3.2.10. Rationale for selection of thematic analysis

Data interrogation aimed to obtain essentialist information (reports of the women), for constructivist interpretation (communication of the events) (Braun and Clarke 2006; Miles and Huberman, 1984, 1994). The inductive, semantic method of thematic analysis was selected for pilot phase 1 to meet this aim.

Outline features of thematic analysis

This was selected as an appropriate method for several reasons:

i. Thematic analysis can be viewed as a foundational method for qualitative analysis (Braun and Clarke, 2006) and is recognised for its flexibility and the potential to produce rich and detailed, yet complex accounts of data.

ii. Thematic analysis is utilised as a method for identifying, analysing and reporting themes (patterns) within data (Boyatzis, 1998), for example women reporting similar symptoms in ovarian cancer.

iii. It is a way of organising data in detail by sectioning these similar themes into corresponding divisions, and in this way highlighting and interpreting various aspects of the research topic (Coolican, 2009; Boyatzis, 1998).

iv. Braun and Clarke (2006) discuss thematic analysis as an *essentialist or realist method* that report participant experience.

v. It can also be a *constructionist* method (i.e. Potter and Hepburn, 2005; Neimeyer and Raskin, 2001) which examines the ways in which events, realities and meanings are the effects of a range of communications within society (GP/patient interactions for example).

vi. It can also be seen as a *contextualist method,* juxtaposed between essentialism and constructionism and characterised by theories which recognize the way people make meaning of their experiences (the interpretation of the meanings from the interviews with the women). Thus, thematic analysis may be used as a method that aims to define 'reality' and also explain the origins and reflections of the establishment of this 'reality' (Willig, 1999).

Braun and Clarke (2006), view thematic analysis as a process of minimally organising data into rich sets, that does not have an allegiance to a specific epistemological position in the same way that other methods, such as narrative analysis or grounded theory do. Research suggests that a lot of qualitative analysis is essentially thematic, but claimed to be something else, such as discourse or content analysis (Attride-Stirling, 2001; Meehan et al, 2000; Boyatzis, 1998).

3.2.11. Rationale for progression from phase 1 to research phase 2

Pilot phase 1 provided a phenomenological interpretation of the women's experiences, via thematic analysis. This usefully summarised key features and highlighted similarities and differences in the experiences of the women. However, thematic analysis, did not impart the level of individual psychological insight that was required to provide depth of meaning (Smith, and Osborne, 2003, 1997). A phenomenological perspective has been used in a number of ways in research (i.e. Giorgi, 1970, 1994, 2000; Smith, Jarman, and Osborn, 1999; Smith, 1996a; Moustakas, 1994; Colazzi, 1978).

Whilst, phase 1 provided a level of understanding on the issues for women, phase 2 would provide depth of understanding. Analysis of individual accounts was undertaken in order to move from a descriptive thematic analysis to a more contextually interpretative analysis of individual cases (Smith, 1996a; Smith; Jarman, and Osborn, 1999). Interpretative phenomenological analysis (IPA) uses in-depth, personal qualitative analysis and Smith et al (1999), explicitly state that it is not appropriate or indeed necessary to provide an absolute methodology for IPA. The basic process in

IPA involves traversing from descriptive to interpretative; it does not seek to claim objectivity, as other methodologies may do via detailed formulaic measures. Smith et al (1999), emphasise that the focus is, "Themes and connections available within the text, rather than attempting to find instances that would fit a particular pre-existing theoretical, viewpoint" (p 231). IPA encourages in depth analysis of small numbers (Smith 1996a; Smith, 2004; Brocki and Wearden, 2006).

In research phase 2, a new small sample of women were recruited in order to explore the depth and richness of participant psychological constructions via interpretative phenomenological analysis.

3.3. Phase 2

Rationale

- To gain insight into the experiences, beliefs and psychological constructs of women with ovarian cancer.

Phase 1 had provided a summary of key features and highlighted similarities and differences in the experiences of the women with ovarian cancer. By utilising the double hermeneutic discussed by Smith (2007, 2004), within phase 2, a more insightful, psychological interpretation could be gained. Interpretative phenomenological analysis (IPA), is a method whereby the psychologist has the opportunity to engage with the actual research on an idiographic level (Bannister et al, 1994). The 'lived experience' is coupled with a subjective and reflective process throughout the interview and analysis, with interviewer and participant both discussing meaning, interpreting cognition, affect and any actions which may have been taken. These interpretations are drawn from the central account of the participant's experiences, their phenomenological world. The complexity of the experiential data is subjected to rigorous and systematic analysis and focuses on the process of individuals making sense of their world. Central to IPA, is the researcher's own interpretation of meaning elicited from the analysis of the participant interview. Smith (1996a), states that IPA aims "to explore the participant's view of the world and to understand and integrate, as far as possible, an 'insider's perspective' of the phenomenon under study" (p. 264). Within health care, this also assumes a "belief in and concern with, the chain of connection between account, cognition and physical state" (Smith, 1996a, p. 265).

3.3.1. Ethics

Ethical approval was obtained from South Cheshire and Liverpool LREC for research phase 2 in 2007 (appendices 9 and 10). South Cheshire ethical committee requested practice is for information and consent letters to be on Trust headed paper, to prove the authenticity of the research. This procedure was followed (appendix 11).

Women approached to participate in the research were provided with an introductory letter, a written information sheet, explaining why the research was being conducted and that interview information was for research purposes only and a consent form (appendices 12 and 13), which was to be signed if they agreed to participate in the research. This was signed and dated by both the researcher and the participant. A copy of the consent form was retained in the case-notes, one was retained by the researcher and one returned to the patient. All data obtained was anonymised and stored in a locked cabinet.

Participants were asked whether they had objections to the interviews being tape recorded and none objected. They were also reminded that they were under no obligation to disclose anything if they felt uncomfortable, and also that the tape recorder could be turned off at any point, if they wished. The original interview tapes were destroyed once the transcripts had been transcribed, validated and analysed.

3.3.2. Population demographics where research took place and transferability considerations

This research was conducted in an NHS Trust hospital in Cheshire. The sampling was purposive, in that any woman who met the inclusion criteria at the time of research phase 2 was invited to participate. All of the women who agreed to participate were from North Wales, Wirral, Ellesmere Port, and Chester, all areas covered by the hospital. The population of Cheshire is 673,781 and North Wales population is 670,800 (Census, 2001), with lower representation of black and ethnic minorities (BME) at 2% in Cheshire and 1.2% in North Wales, than BMEs in the North West (6%) and England and Wales (9%) (Census, 2001). No women from BME groups participated in the research. There was a mixture of middle and working class participants in the research sample, from both urban and rural populations.

3.3.3. Participants

Sampling considerations

Selection of cases is a crucial issue (Silverman, 2006, 2004; Miles and Huberman, 2001, 1994; Stake, 1995; Eisenhardt, 1989) and as in phase 1, phase 2 used purposive sampling. The aim was to obtain a homogeneous group of women who had a diagnosis and therefore experience of ovarian cancer. The rational of screening all cases of women diagnosed with ovarian cancer and then inviting all women who fitted the inclusion criteria (see inclusion criteria below) was to obtain a sample of women at the same stage disease trajectory, who had undergone surgery and chemotherapy and thus experienced similar disease and treatment journeys. Replicability and generalisability (Eisenhardt 1989; Miles and Huberman 1994) were also serious considerations. Miles and Huberman (1994, p. 173) state, "we would like to know something about the relevance or applicability of our findings to other similar settings". However, some researchers suggest generalisability is inappropriate for qualitative research (i.e. Smith, 1996b; Smith et al, 1997; Denzin, 1995, 2001). The research aimed to qualitatively evaluate women's experience with a particular illness, from a specific area of the UK and a cross sectional time point; it was anticipated that the results whilst providing valuable information of possible use to other researchers, would not necessarily be generalisable to another population, region or culture.

The sample size was limited due to the incidence rate of the disease, inclusion criteria and willingness of women to participate. Women with other cancers could have been included in the research; however, the aim was to explore the experiences of a specific group, namely women with ovarian cancer. Small sample sizes are encouraged within IPA to enable depth and interpretation and not necessarily be generalisable (Smith et al, 1999).

3.3.4. Inclusion criteria

In phase 2, potential participants were selected from the hospital database by the researcher. All women coded on the database with a diagnosis of ovarian cancer, who had completed surgery and had undergone chemotherapy were invited to participate in the research. In addition, in order to ensure it was appropriate to approach potential participants', the opinion of the Oncology specialist nurse was sought and women excluded, if the nurse felt it would present any issues for the women.

The database was searched between October 2007 and February 2008, 14 women were identified from the database. Three women were excluded (clinical depression -2, respiratory illness -1). Eleven women met the inclusion criteria and were invited to participate in the research, of which 5 women agreed to participate. Criteria for inclusion are detailed in Table 3.5. This was the same criteria as phase 1, and women were interviewed between October 2007 and February 2008.

Table 3.5: Phase 2 Inclusion, exclusion, selection and screening criteria for participant selection

Inclusion Criteria	**Exclusion Criteria**
Diagnosis of ovarian cancer Undergone surgery Recently (within 3 months) completed chemotherapy Women of any age	Any other major disease Mental disorders Inoperable ovarian disease
Selection	**Screening**
Selection process identified through patient health records	1. Hospital database of patient health records 2. Discussion with Oncology specialist nurse.

3.3.5. Participant information

Information on research phase 2 process and participants are provided in tables 3.6 and 3.7.

Table 3.6: Phase 2

Phase 2- Main study			
1. Women selected from trust database 2. Letter and consent sent to 11 women (no questionnaires)	5 women agreed to participate	5 women interviewed session is tape recorded	*Data analysis* Interpretative Phenomenological Analysis (IPA)

Table 3.7: Phase 2 participant information

Participant	Occupation	Marital status	Stage of disease at diagnosis	age
1	Retired Head teacher	Married	Advanced	66
2	Teacher	Married	Advanced	52
3	Clerical	Divorced	Advanced	46
4	Retired Nurse	Married	Advanced	66
5	Shop worker	Married	Advanced	51

3.3.6. Face to face interview

Procedure

A semi-structured interview schedule was developed (Appendix 14). This was based on phase 1 findings. Interviews were held either in the women's home or in a private office in the Trust, within one month of the participant agreeing to interview. The interviews varied in length, ranging from one to two hours. Summary notes of each interview were made immediately following each interview. In addition, I also kept self-reflective notes, which referred to any relevant issues such as my reflections and the interview process.

Interview process

Women were asked about their knowledge and understanding of their diagnosis, their first signs and symptoms and their perceptions of how this disease had impacted on their lives. Issues which were thought pertinent or important by the researcher were probed further, with the interviewee raising issues and discussing areas as they wished. Certain areas of questioning were targeted throughout the interview and leading questions specifically introduced the areas. Once the subject area had been introduced, the participant was encouraged to discuss the topic with their own prioritisations and interpretations, with prompts from the researcher to expand or clarify issues as and when they arose.

Following interview, I ensured participants were aware of contacts where they could obtain further information and support should they feel this was necessary. For example, support within the local Trust was the oncology specialist nurse, a chemotherapy support unit nearby and various web-sites which could be accessed.

To ensure research qualitative validity was enhanced in phase 2, quality standards were implemented. The standards reflect Braun and Clarkes (2006) quality criteria for thematic analysis, adapted to be specific to IPA as detailed below:

Transcription - The data was transcribed to an appropriate level of detail, and the transcripts checked against the tapes for accuracy.

Analysis - Data were analysed and interpreted, rather than just described. Analysis and data mirrored each other. Analysis developed a story about the participant. A balance between analytic narrative and illustrative extracts were provided.

Writing - The assumptions and approach to IPA were clearly outlined. There was a good fit between the method and analysis. The language and concepts were consistent with the epistemological position of the analysis.

Overall - All analysis phases had the time to be adequately conducted. As a researcher, I recognised that I was active in the research process and kept a reflective diary of my thoughts, feelings and recollections.

3.3.7. Interview analysis

The interviews were tape recorded with the interviewee's permission and transcribed verbatim. An initial analysis was undertaken on each transcript individually, with annotations recorded along each relevant sentence or paragraph, and coded for important emerging themes. These broad themes were fully documented, written up and reviewed again for higher order themes that recurred amongst several of the cases. The identified themes were supported by the examples and extracts from transcripts. Persistent and recurring observations were evidenced across the transcripts, and these were further analysed in order to make sense of the perceptions of the women. The inductive, idiopathic approach of IPA regards participants as experts in their daily life, they are the one who have undertaken and experienced these events and interactions. The process of IPA analysis will now be discussed.

3.3.8. The process of IPA analysis

The aim of IPA, as Jarman, Smith and Walsh (1997), state "to capture our concern with exploring individual participant's perspectives, whilst also recognising the research exercise as a dynamic process, to some extent guided by the interests and concerns of the investigator" (p.141). The inherent and underlying assumption in IPA is that the researcher is trying to learn and gain access to the participant's psychological world. In phase 2, the objective was to gain insight into the beliefs and psychological constructs the women held regarding their disease. Thus the meanings the women attached to these concepts, the underpinning beliefs were crucial to an analytic understanding of the psychological process. Understanding the intricate and often complex thought processes and meanings are crucial in comparison to measuring merely the process and incidence of events (Smith and Osborne, 2003, 1997).

The critical and fundamental factor with IPA is that it is an interpretation (Chamberlain, 2001). Analysis is based on the quality, not quantity of data collected and used. It is an in-depth, multifaceted analysis based on the richness and complexities gained from statements, nuances, verbal responses and opinions made during the interview. It is not merely a description of events or collection of occurrences. The transcript is read several times until the researcher is aware of the flow of conversation and statements. Notes regarding pertinent or interesting responses are highlighted and their significance itemised in the left hand margin, adjacent to the relevant paragraph. This first stage analysis is to gain an overview into what was actually said at interview and gain an overall perception of the interaction, it is similar to a free textual analysis. The researcher is free to assign and interpret meanings to phrases, making notes at the side of the transcript.

At this stage there is no pressure to allocate or divide these meanings up into subdivisions or sections. This initial phase is to merely get an overview of the whole transcript, note use of language, repetition, avoidance etc. What become evident at this stage are contradictions, similarities, emphasis on certain issues and important concerns that the interviewee has made. Comments about these are noted in the relevant margins throughout the transcript. The researcher then begins the whole process again, this time linking in the key relevant words that have been noted in the left margin, and building contextual phrases with more insightful meaning, utilising psychological terminology as necessary and fitting ideas together. Certain themes begin to emerge. Table 3.8 details the analytic process and table 3.9 provides an example extracted from a participant transcript.

Table 3.8: Process and procedure when undertaking IPA

Analytic Process of IPA
Stage 1 Individual interview transcripts read through several times to familiarize researcher with related phenomenon, thoughts and potential areas of interest and significance. Researcher notes comments in left hand margin of script.
Stage 2 Themes which become evident are recorded in the right hand margin. These are themes seen as important to the participant and also relevant to the researcher.
Stage 3 These themes are drawn together by their shared significance and 'clustered' with common meanings. These 'clusters' are then labelled with example quotes from the text.
Stage 4 Clusters and minor themes when referenced by text are tabulated and filtered with significant importance.
Stage 5 These significant concepts, statements, ideas, i.e. 'super ordinate' themes, particularly relevant to the research question, are then selected and non relevant minor themes discarded.
Stage 6 These super ordinate themes' are tabled together to clarify and illuminate the essence of interpretation gained through analysis of the transcript. By comparing and contrasting super ordinate themes, it is possible to demonstrate commonalities and individual differences across cases to highlight links and themes.

Table 3.9: Example of early analysis of participant 3

Initial impressions	**Interview transcript**	**Developing Concepts**
1st order sadness, low self esteem, loss	'I think obviously somebody, in my mind I suppose I was starting to feel unattractive and that just confirmed it that I was no longer attractive to him and there was somebody else there, and he took that opportunity.' (P3)	2^{nd} order Self blame it's her fault; her links with hysterectomy and the loss of her sexual self
Worry, concerned, Anxious, Low self esteem	I am not quite there. I am OK, I feel healthy I would say....if I do anything strenuous my stomach is tender. It is still tender after all this time....I am still down esteem wise because I haven't seen anybody else since we split up.....I am not as confident as I used to be and that. (P3)	Contradiction and anxiety evident. Still worried about health; desire for return to normality; concerns re relationships and the link to self esteem

Participant 3 is mourning the break up of her relationship, for which she blames herself. Themes of low self worth and sadness are repeated throughout much of her transcript, projecting feelings of anxiety and desperation to return to her pre-diagnosis life and normality. Pre-diagnosis she viewed herself as happy, with no rejection from her partner. This was a period in her life when she was confident, with high self esteem and positive about her sexual self. This cycle is repeated throughout the transcript, with recurring themes and contradictions becoming evident. Some passages are more relevant than others, containing rich and revealing data, giving insight into more deep and meaningful analysis.

All the emergent themes are then listed and a connection sought. This clustering of similar themes enables a structured interpretation of meanings to evolve. Whilst compiling these clusters, the researcher must return and cross reference with the transcript and check the analysis and meanings with the actual written words. The process is similar to that of the *constant comparison* method in grounded theory (Strauss and Corbin, 1990). Using, IPA enables the researcher to interpret and make sense of what the participant is saying, utilising examples and comparing clusters of different themes and inferences. The prioritising of these super ordinate themes is then possible from the recurrences, repetition and emphasis the interviewee places on individual examples. For example, in participant 3's transcript, sadness, rejection, loss of esteem and her sexual self, are the highlighted areas that became prioritised by her and the interviewer. However, whereas participant 3 stated she was nearly back to normal and coping well, analysis of her phrases throughout her transcription demonstrated an insight into a frightened, dependent and lonely woman who certainly was not back to normal. Her projected self was very different to her real self.

3.3.9. IPA and the researcher as part of the research process

Epistemological and ontological position should be considered as part of the research process. Within an IPA analysis, Smith (2004) and Brocki and Wearden (2006), state that in relation to IPA, the researcher should outline their background to ensure that the interpretative process is transparent. In addition, this enables others to evaluate researcher interpretations in context. Also, as Elliot et al (1999) discuss, the researcher must be reflective and consider alternative interpretations. To ensure alternative interpretations were given consideration, a recursive 'validity check' was utilised throughout the analysis. The interpretations and comments of my research supervisor, experienced with the use of IPA were also considered in the interpretation of meaning.

About myself as a researcher undertaking IPA research

I am a middle aged, White British female, a part time Ph.D. student and work full time as Head of Research and Clinical Audit, in a United Kingdom, National Health Service, Foundation Trust Hospital. My goal was that of understanding how women with ovarian cancer experience their illness and their interpretations of events. In interviews, I asked open questions and gave non-leading responses to minimise any influence over participant response.

3.3.10. Rationale for selecting Interpretative Phenomenological Analysis

The methodology for phase 2 was based on incorporating a cognitive, linguistic and hermeneutic framework, via IPA analysis (Smith, 1996a).

IPA main features

- IPA is idiographic and specific to individual lived reality. It can make specific statements effective and relevant to the case.
- It is an inductive 'bottom up' approach and forms a dynamic interaction between participant and researcher.
- By combining empathetic and hermeneutic questioning, it can adopt an interrogative style, to obtain participant interpretation of their 'world'.
- It adopts detailed case analysis as an end to itself and is not involved in comparing themes to develop results.
- IPA emphasises the recruitment of homogeneous participants who are

'experts' in the phenomenon to be studied. All research phase 2 women had accumulated substantial knowledge of their experience by the time interviewed.

Smith and Osborne (2004), recognise the power of cognition, phenomenological experience and verbal reports in the reporting of and predicting of subjective experience. Whereas thematic analysis had effectively outlined constructivist themes in pilot phase 1, the double hermeneutic dynamic process had not been developed. Although the main premise of IPA and other phenomenological approaches is to remain faithful to the words and meanings of participants, the role of the researcher in interpreting participant accounts is crucial and encouraged, in order that psychological insight may be generated (Smith, 2004). Hermeneutic phenomenology specifically recognise the role of the analyst as crucial in the interpretation and framing of data analysis (Giorgi 1995, 1970; van Manen, 1990), in order to understand the participant's reflection and structured inference of their experience.

Potter and Hepburn (2005), debate if the data analysis process is neutral and representative of the participant perspective, within IPA, individuals are viewed as 'experts' in their personal experiences (Smith, 1996a). From an IPA perspective for example, only someone experiencing auditory hallucinations can relate what that experience really means to them. So too, with women with a diagnosis of ovarian cancer, as the 'experts' they had experienced, and importantly, conceptualised, how diagnosis and treatment had impacted on their beliefs, expectations and desires.

Sample size in IPA

Smith et al (1999) and others (Brocki and Wearden, 2006; Reid et al 2005; Smith and Osborne, 2003,) suggest that *less* is in fact *more* in IPA, a challenge to traditional qualitative theory. IPA supports the philosophy that "From an idiopathic perspective, it is important to find levels of analysis which enable us to see patterns across case studies, while still recognising the peculiarities of individual lives from which those patterns emerge" (Smith et al, 1999, p 224,). For example, Smith (1999) in his analysis of women's experiences of pregnancy used IPA for an in-depth analysis. The amount of data generated (3 cases), Smith sees as extraneous in comparison to the richness and quality of the data yielded. Amassing large quantities of similar data is viewed as unnecessary, as the aim is to establish *individual* accounts of phenomenological experiences. Thus the specificity of the *lived experience*, uncovered via IPA, for the 5 women, was deemed to have a strong and defendable theoretical standpoint.

3.4. Methodological considerations phase 1 and 2

Reflexivity

Reflexivity is central to qualitative research and acknowledges the researcher's role in the development of knowledge. Reflexivity played a large role throughout the research. As the researcher, I kept a diary of my thoughts and reflections throughout the data collection and analysis periods. My role in the process and analysis was considered carefully. In particular, the way I interacted with the participants and the data to produce the findings. In addition, I considered differences between myself and the participants in background, education, language and experiences and how this might influence my interpretation. Via engagement in IPA and reflection, I ensured as much as possible that my findings reflected participant accounts (Smith, 1996a, 1997).

Validity of data

The British Psychological Society provide online guidelines for assessing quality in qualitative research (BPS, 2008), yet criteria for assessing qualitative research is a controversial area, with concerns that rigid criteria limit freedom and stifle methodological development (Parker, 2004; Smith, 1996b; Stiles, 1993; Henwood and Pigeon, 1992). However, Miles and Huberman (1994), cite the cornerstones in validity testing as being representativeness, reliability, reactivity and replicability.

Triangulation is a popular validation method involving use of data drawn from several different contexts i.e. researcher, theory and method. Analysis of interviews from both phases 1 and 2 and the narrative literature review, have provided triangulation via these multiple evidence sources on the experiences of women with ovarian cancer and added to the research validity (Yin, 1994). Triangulation is recognised as an effective validation tool (Miles and Huberman, 1994; Braun and Clarke 2006); however, Silverman (2006) criticises triangulation as potentially flawed, as each method utilised in data collection relies on the same reliability factors and may be equally inconsistent i.e. the researcher may be poor at recording interviews and inaccurate in analysing questionnaires. Furthermore, the accuracy of one approach, does not cancel the inaccuracy of another approach and the aggregation of data, even within a similar theoretical perspective may fail to produce an overall truth. In other words each method may be inconsistent or unreliable and Silverman emphasises the importance of *understanding* and not *judging* the truth. Silverman (2006) also cites problems with individuals interpreting things differently and highlights the importance of generalisability and selectivity in sampling, as effective in developing empirically valid findings. Miles and Huberman (1994, p. 173) state, "we would like to know something about the relevance or applicability of our findings to other similar settings". However, there is some debate, with a suggestion that generalisability may be inappropriate for qualitative research (i.e. Smith, 2007, 2004; Smith and Walsh, 1997; Denzin, 2001, 1995).

Yardley (2000) takes a realistic stance suggesting validity should be cross-referenced and provides a 3-point checklist:

1. Sensitivity to context – researchers should show an awareness of theory and substantive evidence.
2. A robust research commitment, rigour and transparency.
3. Impact and importance, does the data make a contribution to the area.

Whilst recognising that Yardley (2000) has made a useful contribution towards the question of quality and validation applicable to any qualitative data, Smith (2007) reiterates that any interpretation is subjective and influences how theory and data are incorporated.

Yin (1994) suggests that how data will be analysed is important and that an analytic strategy with evidence or audit trail for validation of method is required. In this way, Yin (1994) suggests that some evidence of quality and validation can be provided by compiling all documentation and making this available to an independent observer. Within this research, homogeneity was sought and purposive sampling was utilised in both the pilot phase 1 and the main research phase 2, as I was interested in the experiences of women with a diagnosis of ovarian cancer. IPA focuses on individual 'lived experience' and not necessarily generalisability to other populations (Brocki and Wearden, 2006). Furthermore, some qualitative researchers suggest generalisability is generally inappropriate for qualitative research (Denzin, 1995, 2001) and inappropriate to IPA specifically (i.e. Smith, 1996a; Smith et al, 1997).

Smith (2007, 2004) and others (Brocki and Wearden, 2006; Reid et al 2005; Smith and Osborne, 2003,) suggest that *less* (participants) is in fact *more* (quality) in IPA, a challenge to traditional qualitative theory. In addition, the research methodology described in this chapter, incorporated the recommendations for qualitative research to ensure quality of Braun and Clarke (2006), Smith and Osborne (2003, 2004) and the British Psychological Society guidelines (BPS, 2008).

Analysis of data

Analysis of the data is the so called 'heart building' of the theory from case studies (Eisenhardt, 1989). Miles and Huberman (1984) define data analysis as occurring in three stages:-

1. Data reduction – as part of the analysis process
2. Data display – to reduce and display the data in an organised way
3. Drawing data conclusions – but remaining open to meaning

Data validation in some of the other qualitative methodologies such as grounded theory may have included discussing and gaining feedback on researcher interpretation and findings; however, this is not congruent with IPA. Smith (1996a, 2000); Smith and Eatough (2007) and Brocki and Wearden (2006) view IPA as focused on researcher interpretation of participant psychological constructs and cognitions. The preferred quality control procedure within IPA is that of the 'audit trail', as opposed to external validation (Smith, 2003). The rationale for this is that anyone else checking interpretation may not have a full understanding of the research context. The audit trail is therefore not for confirmation of analytical interpretation, but clarification of the research methodology to establish the quality of the analysis. Within the current research, my supervisor reviewed and discussed the methodology and methodological assumptions throughout the research process.

Participant validation was not sought. A theoretical reason provided by Giorgi (2006) and Merleau-Ponty (1964) for the participant not being an analysis verifier, is that the individual who *experienced* the event, may not be the best judge of the *meaning* of the experience. Skilled researchers have expertise and knowledge gained via their discipline, making them better verifiers of the meaning of their data, than external judges or even the participants themselves. In addition, due to the content and emotional nature of some of the themes and participant admissions that had emerged in some interviews, participant validation may have proved distressing for some individuals and I would have viewed this as an ethical issue (APA, 2002; BPS, 2004).

3.5. Qualitative research methodologies considered

Following the information provided on the breadth of the experiences of women with ovarian cancer, in the pilot phase 1, it was recognised that there were numerous forms of qualitative methodology available that would provide a rich and meaningful analysis for the main research phase 2. Although, in-depth IPA (Smith, 1997), was chosen several alternatives were considered, from the numerous qualitative methods available. Cresswell (1998, p.4), has stated that the array of qualitative methodologies available is 'baffling'. The alternatives considered were grounded theory (Glaser and Strauss, 1967), discourse analysis (Parker, 1992, Potter and Wetherell, 1987) and phenomenology (Giorgi, 1995). Whilst these methodological approaches have some differences in philosophical underpinnings, grounded theory, IPA and phenomenology focus on the *meaning* of data to provide insight and understanding. The focus of discourse analysis is on the *function of language,* in constructing meaning. Why IPA was selected as a research methodology, in relation to other possibilities will now be discussed.

Discourse analysis looks at how language is used, not cognitive explanations for the processes involved in social interactions. Therefore the influence of cognitions on language and behaviour are not considered. Discourse analysis focuses on how individuals construct meaning through the function of language. There are two forms of discourse analysis, discursive and foucauldian. Discursive analysis (Potter and Wetherall, 1987), focuses on the practice and the 'action orientated' nature of language; the way language is used, such as to debate persuade or encourage. Foucauldian analysis (Parker, 1992), aims to evaluate available resources and how language discourse constructs the social world. As I wished to explore the experience of women with ovarian cancer and include cognitions and interpretations, discourse analysis was rejected as a research methodology.

Grounded theory (Glaser and Strauss (1967) aims to encourage the generation of theory from categories of individual and detailed descriptions. It provides a means for eliciting meaning and describing psychological and social processes, used in individual sense making of their world. Grounded theory has elements of positivism, with the use of systematic techniques to gather data and interpretive elements, and the attempt to understand action and intent. There is also a link with symbolic interactionism, by recognition that individuals have capacity for reflection, choice and action. Constant comparative analysis is used to check category groupings. Emergent theory is developed as data is analysed. Data is collected and analysed until no new categories emerge. Within grounded theory, much debate has occurred, with two different perspectives emerging on data analysis. Strauss and Corbin (1990), produced a guide on data patterns, detailing how categories could form a structure, via the use of higher order codes. Glaser (1992) objected to this method as limiting the way data could be analysed and the fact that patterns of categories should emerge from the data.

IPA and grounded theory share some similar features, for example, both IPA and grounded theory begin with individual cases, and they both use categorisation to reduce data such as emergent themes and produce understanding into the fundamental processes involved in individual experience. In addition, *epoch* is central to IPA and grounded theory (and phenomenology). Epoch relates to the researcher attempting to be objective, to avoid pre-supposition on the research topic. On this point, Willig (2001, p. 53) notes that the researcher must be aware of the difference between introspective attention or contemplation on a participant experience and the analysis of a participant experience.

Phenomenology, as postulated by Husserl (1925) focuses on the experiences of individuals, within particular contexts, at particular times. Leonard (1994), states that "The ultimate criterion for evaluating the adequacy of an interpretive account is the degree to which it resolves the breakdown (in human affairs) and opens up new possibilities for engaging the problem" (p. 60). The central aim of phenomenology is to capture as closely as possible the way a phenomenon is experienced by an individual (Giorgi, 1970, 1995). It seeks to reflect meaning in individual thoughts, feelings, emotions and experiences and is aimed at discovery, not hypothesis proving or theory testing (Giorgi, 1970, 2003). In the analysis of phenomenological data, an emergent strategy is used, to facilitate analysis following the data. The focus is on understanding attached *meaning*. To obtain this, a common approach is to identify from participant narrative, emerging themes. Only those theme elements crucial in understanding *meaning,* contribute to the theme.

In choosing a research methodology, I aimed to obtain a rich and detailed insight in exploring the experiences of women with ovarian cancer. I rejected grounded theory (Glaser and Strauss, 1967) as it is not sufficient to describe individual experience; research should contribute to theory generation. In addition, grounded theory recognises specific social processes that account for phenomena and whilst being particularly appropriate for sociological research, I did not feel that it would meet my research methodology requirements. In contrast, phenomenology would have provided some aspects related to individual *meaning*, but I felt that IPA would give a richer, more detailed analysis. The premise of IPA is that individual cognitions are not necessarily evident from the interview transcript. Therefore, the process of IPA is to map the verbatim record with the underlying cognition, to provide depth and understanding of the psychological processes involved and like grounded theory, it involves researcher reflexivity, which is important in the analysis process.

IPA is focused on deep and rich psychological interpretation. However, IPA does not contribute to theory generation, as grounded theory does. IPA has been increasingly used in the field of health psychology research (Smith, 1996a, Smith et al., 2003, Smith, 2004), and provides a theoretical framework, in keeping with the exploration of the experiences of women with ovarian cancer, from a psychological perspective. Other qualitative methods were considered, for the research methodology, following due consideration, IPA was chosen for the research methodology.

3.6. Summary

In pilot phase 1, questionnaires and face to face interviews were used to explore the *breadth* of experience of women with ovarian cancer. In phase 2, face to face interviews were subjected to an *in-depth* IPA, to explore the psychological interpretations and cognitions of women with ovarian cancer.

CHAPTER FOUR

Results Phase 1

4.1. Introduction

The results for the pilot phase 1 are presented in this chapter. The rationale for phase 1 is provided in chapter three.

4.2. Participant questionnaires

The questionnaire was sent to all women who met the inclusion criteria (see chapter 3), 28 questionnaires were mailed to potential participants and 15 questionnaires were returned. Table 4.1 details the questionnaire results.

Table 4.1: Participant questionnaire findings

Item	N women
Contraceptive pill	3/15
Hormone replacement therapy	8/15
Recollection of signs and symptoms prior to diagnosis	
bloating	9/15
bowel problems	7/15
abdominal pain	5/15
back pain	10/15
urinary symptoms	12/15
Dissatisfaction with time taken for GP diagnosis expressed	11/15
Satisfaction with time taken for GP diagnosis expressed	4/15
No prior knowledge of ovarian cancer	13/15
Information seeking on the internet post diagnosis	2/15

4.3. Analysis of participant one to one interviews

A final question on the questionnaire asked women if they would be willing to be interviewed for the research, 13 (13/15) women agreed to participate in an interview.

Table 4.2: Phase 1 participant information

Participant	Occupation	Marital status	Stage of disease at diagnosis	age
1	Healthworker manager	Married	Early disease	52
2	Taxi driver	Divorced living with new partner	Advanced	44
3	Housewife pregnant	Married	Advanced	43
4	Retired	Married	Advanced	68
5	Retired	Married	Advanced	70
6	Teacher	Married	Advanced	52
7	Retired	Married	Advanced	68
8	Retired	Widowed	Early	70
9	Retired	Married	Early	67
10	Retired	Married	Advanced	69
11	Retired	Married	Early	71
12	Clerical	Married	Advanced	58
13	Retired	Married	Early	69

The interview allowed a rich level of data to be gathered and thematic analysis identified the following themes:-

1 - Physical signs and symptoms

2 - GP interactions

3 - Hospital treatment and hospital experiences

4 - Family members/partners interactions

5 - Psychological interpretation of the experience

Participants expressed differing views and attitudes towards their disease trajectory and these issues are highlighted with opinions and quotes from individual participants. Table 4.3 details the themes.

Table 4.3: Thematic analysis identified major themes and sample comments

Theme	Comments	Number of women	Time range
Physical signs and symptoms	Bowel changes urinary changes vaginal bleeding pain increase in girth dyspnoea	13/13 experienced 3 or more symptoms	1 week to >12 months prior to visiting GP
GP interactions	Non examination Not taken seriously Not referred Repeatedly given antibiotics Referred for 'wrong' investigations	8/13 reported satisfied with GP treatment 5/13 were dissatisfied with GP treatment	Stated 1-13 visits up to 12 months prior to diagnosis Varying time scales for consultation
Hospital experiences	Not as bad as expected Relieved to have surgery All agreed to have chemotherapy	13/13 pleased to get on with treatment	8-10 month period From surgery to completion of chemotherapy
Family/partner interactions	Discussion of diagnosis and prognosis between spouses; some women refused to discuss, others wanted transparent relationship	10/13 women thought their partners had looked up ovarian cancer on web but didn't discuss with them 3 husbands had been on web and did discuss with wives	From diagnosis through to interview with researcher
Personal psychological interpretations	Most were positive about future Most reflected on negativity of not going to doctor earlier Emotions of denial, anger, fear, sadness expressed by most women	11/13 positive about prognosis, 3/13 possibly unrealistically positive 2/13 realistic in that prognosis palliative only	From pre-diagnosis to interview with researcher

4.4. Identified themes

a. Theme 1 physical symptoms

Identified theme 1 was physical symptoms, changes in bowel habit, urinary problems and abdominal swelling. These are all discussed with reference to individual participants.

All women (N13) admitted recognising and experiencing more then 1 abnormal physical symptom in the months prior to their diagnosis. There was no uniformity in the particular symptom or in the individual prioritisation of the complaints. Some women (N11) tolerated, and in some cases normalised, the symptoms for many months. Participant 1 stated she could put up with backache, abdominal cramps and pain on intercourse, and indeed did for nearly 5 months. But it was the urinary problems, creating a degree of incontinence which she personally saw as the greatest inconvenience. This, plus one episode of unexpected vaginal bleeding drove her to seek advice from her GP. She reported she would probably have put up with all the other symptoms for a great deal longer. By taking analgesics, she could to a certain degree, control the pain and 'normalise' her daily roles. She had a senior managerial job which entailed long hours and many meetings travelling over a large geographic area. Her explanations for delay centred on time constraints, She had teenage children, this plus the job left her little time; she 'couldn't afford time to be ill' (participant 1).

Participant 2 self medicated for several months prior to seeing her GP. The bowel changes, alternating diarrhoea and constipation, were 'controlled' to a certain degree by over the counter medications from her local chemist. She stated she thought for a while *she* was at fault by making her symptoms worse, too many tablets for constipation would result in diarrhoea. However, zealously treating the diarrhoea would result in constipation. Diarrhoea is not a complaint that is easily accommodated with the job of taxi driving, and she viewed this symptom as a priority over repeated urinary infections and vaginal discharges. She eventually sought GP help with a vaginal infection when the smell became a problem in her taxi, and was prescribed a course of antibiotics. She did not at this time mention any other symptoms to him as she thought they were un-related and irrelevant. The advancement of the disease and her general decline in health following on from this, she 'blamed' on the antibiotics as they had initially made her feel sick. Four months passed and it was her increasing girth that then became the priority. She explained this to herself as being due to wind, constipation or just putting on weight, but admitted driving did become a physical difficulty. Eventually when the swelling abdomen would no longer allow her to bend down to pick up the washing for example, the symptoms could no longer be ignored and she finally made the decision to see her GP.

On reflection she admitted that all these symptoms were abnormal and probably should have been addressed much earlier. But as with many of the women, if they were able to carry on with their daily lives, albeit aided with analgesics, laxatives, anti spasmodic etc., they did not seek medical help. She at no time associated all the symptoms together stemming from one main source. They were all seen and treated as *individual* complaints with *separate* causes for which she tried to develop her own explanations, and apply her own treatments.

Participant 7 denied her symptoms as being problematical until a couple of days prior to awaking in the middle of the night unable to breath and being taken into hospital on a 999 call to have her chest aspirated (fluid accumulation from secondary deposits). She admitted she had 'guessed' for many months that 'something was wrong' but didn't know exactly what. She was frightened of the diagnosis and asked her GP outright at her first consultation 'was it cancer'? (This was her first visit to him, where he examined her and made an urgent appointment with the hospital consultant. Her emergency admission pre-empted this two days later). Interestingly, her daughter was a doctor working in the South, but the participant stated she 'didn't want to worry her children', a common statement from all women referring to children or partners. This woman, a retired teacher, observed each new symptom as it arose and tried to attribute it to menopause, middle aged spread, inactivity, various 'virus', and never shared her fears with anyone. It was an 'internal' cognitive personal analysis, and she admitted she had spent many hours engaging in this psychological private argument trying to convince herself that all was well.

Participant 4 attributed her symptoms of nocturnal dysuria to caring for her terminally ill mother. The elderly mother lived with her for several months and called for attention regularly 6-7 times throughout the night. After tending to her mother, she would visit the toilet prior to returning to bed. After her mother's demise, she continued to get up several times a night to visit the toilet, before realising it was not just a habit evolved through a disruption in her sleep pattern. This marked abnormal urinary symptom, together with a swelling abdomen, was the driving force for which she sought help.

The rationale for women not prioritising these symptoms is interesting:

- Too little time in a busy day with many competing 'other factors' such as family, work.
- Fear, knowing 'something' was wrong but not knowing exactly what.
- Other more pressing issues, for example her ill mother.
- Being able to 'control' the symptoms (albeit it temporarily) with medication or changing life style to accommodate abnormality.
- Ignorance of genuinely not knowing anything was seriously wrong.

Participant 8 was admitted as an emergency with several litres of ascetic fluid creating pressure in her abdomen, "I just wanted to get Christmas over, and then I was going to make an appointment" (with the GP).

Participant 11, a particularly shy, private woman found wind the greatest problem. She tolerated indigestion, backache and abdominal discomfort without too much of a problem. She coped with a hugely increasing girth by altering her skirts and trousers and devising elastic bands and hooks to expand as her waist increased nearly 4 dress sizes with the swelling. But it was the terrific 'abnormal wind reactions' she found most distressing. She watched her diet 'like a hawk' and on holiday, refused to go out of the hotel room at all because of the wind and the increasingly erratic bowel responses. She stated it was this embarrassment of talking about her bowels and wind that deflected her from seeing her doctor. She eventually made an appointment with the practice nurse who 'diagnosed' IBS and gave her a diet leaflet. However, the swelling abdomen eventually took precedence and forced admission.

Fear of embarrassment took priority here over fear of something being seriously wrong. During interview, the participant went to great lengths describing how she and her husband had created the waistband expanding devices on her clothes without ever actually discussing the *reason* for the need of the device. When drawn back to this point, she smiled and said she thought she was putting on weight and it was due to the wind. But then, with hindsight, she stated at the back of her mind she thought 'something, '*not cancer*' might be wrong but was beginning to accept IBS as the diagnosis and blamed that. When asked if she hadn't been urgently admitted to hospital, how long she would have left it before going back to the GP, she replied she 'didn't know', but did not have any plans to make an appointment in the near future.

Other women did take note of their symptoms quite early on, and were worried enough to visit their doctors. This led onto the next theme.

b. Theme 2 GP interactions

Many participants (8/13) reported at interview that their meetings with the GP had been good, productive and the doctor had acted on their information and referred them to a specialist. They had received 'what they expected' (participant 1). These women arrived at the surgery with symptoms, were examined and referred appropriately to gynaecological consultant. But these women were all in advanced stages of disease presenting with marked abdominal masses and ascites, dyspnoea and anaemia. None had attended previously, and all stated the GP's had been 'excellent', 'wonderful', 'efficient', and 'quick off the mark'. But was this praise for the GP's in fact a reflection of a feeling of guilt from the women? Did they subconsciously recognise they had allowed the disease to progress to this late stage before seeking help, accept they should have attended much earlier? Thus *any* response which activated the diagnosis/ treatment process may have been viewed positively and with a great sense of relief from these scared and sick women. All were asked by GP's how long they had been aware of their individual symptoms and reported between a minimum of 3/4 months, with others stating over 12 months.

The other 5 women, who interestingly attended *earlier in* their disease, did not have such good experiences to relate. Participant 8 first went to her GP with a complaint of increasing girth; her skirt size had increased by three sizes (Normally a size 12 she had graduated up over a matter of months to 18). He didn't examine her but told her to lose weight. She stated he was so 'dismissive', she changed GP and saw the new one a couple of weeks later.

She was again not examined but referred to dietician. She returned 6 weeks later with worsening complaints requesting a hospital referral as she knew something was not right. This was denied with the GP saying it was not necessary. She had still not been examined. Whilst on holiday a couple of weeks later, she was standing on a packed bus and an elderly woman offered her a seat, commenting about her being heavily pregnant. This reaffirmed to her that her shape was certainly abnormal and something was seriously wrong. She returned to her GP demanding a referral and threatening to write to the hospital herself. Reluctantly, the GP agreed (without examining her) but requested a non urgent appointment which took three months. Nine months passed from first GP appointment to consultant referral. Participant 6 had noticed problems for approximately six months:

> "Well in a way, my tummy was getting bigger you see and I put it down to menopause because you do don't you? And then I went for this facial and they said 'would you lie on your tummy?' It really hurt to lie on my tummy. I didn't take any notice. Then I got this pain shooting down my side and I thought I felt a bit uncomfortable and I thought I'd better go to the doctors. Anyway I went to Dr X, a fantastic doctor, he was on the ball and just pressed my tummy and I nearly went through the roof. He said we will send you to see the gynaecologist and that was it". (participant 6)

Participant 9 had been visiting her doctor for over a year with the same painful symptoms. She was never examined and told it was sciatica. She had increasingly painful urine infections and abdominal pain but was told:

> ".....it was due to old age. I must expect things - namely aches and pains -to go wrong at this stage ..." (participant 9)

She was eventually admitted as an emergency. A feeling of being dissatisfied but not knowing exactly of how to manipulate the system was evident. The participant was very aware of the power structure of the organisation and felt impotent to deal with it. Following surgery and chemotherapy and a poor prognosis she commented:

> "I know this sounds very bitter but I've had enough of the medical people for now. I was sadly disappointed at my treatment from my GP. I knew all along there was something, I kept getting painful water infections towards the end, and still I was passed off. They could have taken it further a lot sooner. Maybe it would have helped me. I got scared of complaining in case I would get thrown out of the practice". (participant 9)

Participant 10 visited on a regular monthly basis, complaining of changes in bowel habit and increasing girth. She was a retired teacher and saw several different GP's in the practice and was given a diagnosis of IBS. Medication/diet made no improvements and she demanded referral, making a private appointment in the hope this would be quicker. Following hospital examinations which ruled out IBS, she revisited her GP and it was suggested she try anti depressants as she appeared to be becoming very anxious. This offer she declined. Frustrated but concerned by her breathlessness and swelling abdomen she returned to make an appointment with a female GP she had not yet seen. This GP had just lost her mother who had died of ovarian cancer. She recognised and suspected the symptoms as being of ovarian origin, referring immediately. The woman stated that following all her interviews with several different doctors, who all concluded with the same diagnosis of IBS, menopause, wind, she did think she was perhaps 'losing her mind'. One night as she sat up in bed trying to get her breath, she did indeed wonder if her decision to decline the antidepressants had been the right one and "was it all psychological?" It was 14 months from her first GP appointment to diagnosis.

Once a diagnosis has been recorded in the GP notes, in this case IBS, medical opinion appears to be swayed by this until another diagnosis *proves* itself to be strong enough to displace the original. And it appears to be the women themselves who have to convince the GP of their symptoms. Some of these participants were articulate, intelligent women, others were elderly, of a socioeconomic status that *knew*, but could not verbalise their problems.

Other participants talked of 'luck' in their diagnosis, 'lucky' her usual GP was on holiday when she made her appointment and saw a locum GP who was 'on the ball' and referred her quickly. Another participant demanded further investigations and she believed that her GP reluctantly made a non-urgent appointment for a scan. She said her 'luck was in' as snow made many people cancel their appointments. She lived nearby the hospital and was contacted by phone to see if she could take one of the cancelled slots. Thus her diagnosis was made much earlier and she attributes her good prognosis to the 'luck' of bad weather. Other participants talked of being 'lucky' to have made appointments with a 'good' GP when finally something was done and they were referred to specialists.

The underlying assumption of 'luck' assumed by these women does not demonstrate feelings of confidence or assurance in their GP's. They voiced that they considered themselves fortunate to have had a referral/diagnosis made when non routine circumstances intervened. However, this was this a retrospective analysis they had made several months later when they were certainly much more informed regarding ovarian cancer, early symptoms and prognosis following late diagnosis. The women may in fact be mirroring their prognosis (both of these women had good prognosis).

c. Theme 3 hospital experiences

All women (N13) stated the surgery was not as bad as they'd expected. 2 participants had undergone hysterectomy with retention of ovaries several years previously, but most of the other women underwent hysterectomy and bi-lateral oophorectomy. To these women it was, "A relief to get it over" (participant 1).

These were women who had experienced uncomfortable and painful symptoms for many months, so in comparison, they reported transient post operative pain, albeit it temporarily distressing, was not a major problem. They felt they could now move forward, ".....something had been done at last" (participant 10). One woman (Participant 3) was 20 weeks pregnant when the tumour was discovered on routine scanning, and her reaction was very different to the other women. Whilst the other women were looking forward to surgery removing the tumour and affected organs with a positive note, this woman was terrified that the surgery would precipitate loss of her unborn babe. She was aged 41 years and had experienced considerable difficulty in conceiving. Major abdominal surgery to remove the ovary and tumour was not without risk and she recognised this. The ascetic fluid plus a twenty week pregnancy, was creating considerable pressure in the abdominal cavity:

> "I was terrified of the op, but they took the tumour and the tube away, it was the size of a melon. I recovered pretty quickly and was home in a few days. Then I had the results and Mr X explained it was cancer..." (participant 3).

There was then the question of her undergoing chemotherapy prior to her having a scheduled 34 week caesarean:

"They were going to give me chemotherapy but I wasn't very happy at that, you know, what effect it might have on the baby" (participant 3).

She went on and underwent delivery of the babe at 34 weeks with a hysterectomy and removal of the other ovary and tube. Tumour was also discovered in the second ovary with multiple seeding throughout the pelvis. When questioned about the two operations:

> "...I think the first op was probably the worst – worrying whether he (the baby) was going to survive or not. I don't think the diagnosis had really sunk in; I was just worried about the pregnancy and my husband. I felt I'd let everyone down. Then of course I had to wait another 13 weeks for the second op and those last few weeks were hard. I was having lots of pain and discomfort and constantly worrying about the baby. Mentally I was just trying to be strong and get through it for my family." (participant 3).

The pressures of this woman put her apart from the other women and her perspectives were completely different. Interestingly she did comment that she was glad she was pregnant when the tumour was found. She rationalised that if she hadn't have been pregnant it might never have been found by routine pregnancy scanning. She denied experiencing any abnormal symptoms, but stated she had developed several urine infections. Any symptoms, e.g. abdominal swelling, ascites, would have been masked by the pregnancy and thus she viewed herself as asymptomatic. She also stated that after all the treatment she had the baby to look forward to and 'take her mind off things', whereas the other women had nothing. This conclusion may have been reviewed as disease progression became obvious.

Other women found waiting for the histology results the worst part:

> " ...I think the worst for me was when I had to wait for the results of the blood tests, and I think 10 days is a long time to wait. Half way through I just broke down and said 'you have just got to tell me what is going on 'because that's the killer, the waiting" (participant 6).

Other participants also found the waiting for confirmation very difficult. They suggested that they had *suspected* cancer prior to admission, and then were *informed* by medical opinion that it was *'likely'*. Following surgery the histopathology was going to be the proof they all feared.

Due to the early discharge regime in the hospital, all were discharged from hospital prior to histopathology results and had to return to clinic the following week for this clinical information. They also at this time, made subsequent appointments with the oncologist to commence chemotherapy. All women reported they were pleased to leave hospital, and felt the 'major hurdle' of undergoing the surgical procedure was behind them. Whilst the operation findings had been explained to them by the surgeon, and the '*probable*' malignancy explained, with the '*likelihood* ' of chemotherapy to follow on over the next few months, they all stated they existed in a state of limbo. Not having a definitive histopathological diagnosis still meant that they didn't have all the information they needed to assimilate the evidence.

Participant 2 said the 'bad news' of the pathology results from the Consultant was difficult to accept. Even though she had 'guessed' it was going to be bad, until actually *told,* she still clung to the hope it wasn't going to be cancer. Following her first consultation with the Medical Oncologist, she reported his news to be 'good' and 'hopeful' as he talked about her 'treatment'. Her interpretation of the concept of 'treatment' was very different from the reality that the oncologist was discussing. She assumed that if her condition was to be *treated,* it was to be *cured.* His explanation that her chemotherapy was for palliation only, made her very angry and she channelled this anger onto the oncologist stating she 'didn't like him' and 'he was too blunt'. In this way she manipulated the 'unfairness' and anger she felt about her situation, i.e. her terminal cancer, and found someone to blame. It was the Oncologists fault, he was only able to give her drugs to *control* and not *cure* the disease:

> "I felt really angry at first, I'd had the op and then there was all this palliative nonsense. Nobody knows, really knows what's going to happen and for him to just walk in and say that's it – end of story – no chance of cure....just give me more time....I felt like hitting him...I told him – I don't care if my hair falls out, I don't care if I have to crawl around on all fours all day and feel sick, I just want to live long enough to see my girls grow up. I said to P, I don't want anything to do with that man (oncologist) I'll see other doctors, but I don't want to see him" (participant 2).

Moorey and Greer (2002) discuss anger being generated if the person believes their personal domain has been attacked, in this case by terminal disease. The angry person is concerned by the unjustness of the threat being faced, and by focussing on external violations such as the oncologists inability to cure, they are thinking less about personal vulnerability or imperfections. This participant had no idea that she wasn't going to be cured, and when the oncologist came in and explained what palliation meant, she was devastated. All her feelings of frustration, anger, impotence and fear were directed at him.

Only 3 participants did not fall under the criteria to undergo chemotherapy. Ten underwent six cycles of chemotherapy as outpatients. Their response to this was certainly less positive than the surgery, 'pretty grim', 'awful' and 'hard 'were descriptions used repeatedly, but also the women stated it was something they knew they had to go through. They talked about 'tolerating' the side effects and 'getting on with it' because it was 'a means to an end'. There was also a sense of camaraderie mentioned by several women whilst undergoing the chemotherapy:

> "The gang I was in with, we had such a laugh. We called ourselves the Priory Girls and said we were going to do a calendar" (participant 6).

They got to know each other during these sessions and kept in touch during treatment. But friendships drifted after completion of treatment:

> "But we all kept in touch for a while afterwards, but it seems to have drifted which normally happens anyway doesn't it with people?" (participant 6).

This participant stated she was apprehensive at starting her treatment:

> "I have to admit I didn't know what was going to happen. Then when you come in for your other sessions you could always see the first timers and I would ask 'first time?' and 'you'll be alright, don't worry about it' " (participant 6).

She saw her role as supporting other women, and went to great lengths to entertain and reassure other participants:

> "At Christmas I had flashing Father Christmas earrings, and my husband bought a spiral Father Christmas which we had on the trolley and I was whizzing up and down" (participant 6).

Greer & Watson (1987) identified five common adjustment styles that people with cancer adapt or develop:-

- *Fighting Spirit*
- *Avoidance or denial*

- *Fatalism*
- *Helplessness and hopelessness*
- *Anxious preoccupation*

These are evident through statements made and highlight, for example, Participant 6's attitude through most of her treatment. *Fighting spirit* where the individual views their illness as a challenge and has a positive attitude towards the outcome. They take an active role in their recovery and try to live as normal a life as possible. By engaging in positive behaviours, the individual can exert some control over the stress and the prognosis is seen as optimistic. Participant 6 laughed her way through surgery as being one of the 'Priory Girls', and her response to the diagnosis of cancer and her knowledge of her disease was:

> "I'm a great believer in that I think too much knowledge is dangerous. I think you need to know what you need to know, otherwise a lot of people blow a lot of things out of proportion. So I just took it as it came....After he (oncologist) explained, I just got on with the treatment.....That's how I worked" (participant 6).

The woman chose not to look up any more information, relying only on that given by medical staff; she knew her husband had searched the internet but did not want him to tell her details. Her coping strategies were to focus on things she could control, she pointed out that she wore her makeup throughout her chemotherapy and spent a considerable time at interview complaining bitterly about the wig service:

> "Well I was so upset; I was vulnerable, because you are vulnerable at that stage...... I burst into tears....When people have wigs from that hospital they put them in clear plastic bags for them to take away....They should have pretty little bags with tissue....It looks like a dead cat or something...I think that's despicable....women should be

> made to feel special....That's the only complaint I had about the whole experience" (participant 6).

These may be viewed as *avoidance or denial* behaviour, were the individual denies the impact of the disease. The threat from the diagnosis is minimized and consequently the issue of control is irrelevant and the prognosis viewed as good. But as Participant 6's hair dropped out, and she lost her eyebrows and eyelashes, the toxic effect of the drugs became evident and consequently the seriousness of her condition was difficult to ignore. Her anxiety, bursting into tears, was channelled into her irritation and blaming the uselessness of the wig service. The seemingly trivial issue of the not having a pretty bag and tissue paper to carry the wig home in, became her focus point, avoiding not having to think about the real issues. She also commented during interview that she'd agreed to participate in other research relating to recurrence of disease, and when asked to expand her feelings around this area, she responded again with more avoidance techniques:

> "Again I'm not thinking about it. I have had the operation and the all clear and I feel well, so what is the point? If you are going to worry about it you can worry yourself into the grave can't you...I think breast (cancer) is worse than ovarian isn't it?" (participant 6).

Interestingly, this woman was adopted and never knew her birth mother. The trace she did in later years revealed her birth mother had also suffered from ovarian cancer. But she went to great lengths to state her mother *died* of throat cancer and *not* ovarian cancer. Participant 6 had undergone major surgery and completed six cycles of chemotherapy where she experienced complete loss of all body hair, and yet she reported the worst thing about chemotherapy was the difficulty she found swallowing the anti-nausea tablets:

> "The first time I could not get them down because they were so small they stuck in my throat, so I didn't take them. By Saturday I was heaving my heart out. So J rang Clatterbridge and they said she has got to get them down....as I said to them, why they can't coat them...." (participant 6).

She eventually managed to take them with porridge and that was the initial advice she gave to all new women when they came for treatment, "You'll be alright, don't worry about it. Take your tablet with porridge." (participant 6). Despite the gruelling months she'd endured, she brought this distraction up as a real issue stating it as a huge problem and also assumed other women had experienced similar struggles.

Participant 5 also avoided the main issue of diagnosis, being told she had cancer, stating she didn't think of her symptoms as being due to cancer and consequently didn't ask any questions:

> "They didn't say anything, all they said was 'I can't see anything having spread' and I still hadn't twigged what he was talking about. The only time I twigged was when I came to the Consultant and the lady X, she had the name Oncologist on her badge and that was when it twigged. ....nobody mentioned the word cancer" (participant 5).

She didn't pursue the matter, even though she thought it was looking more likely to be a cancer diagnosis, and when asked by the researcher if she requested clarification from the doctor:

> Interviewer "And did you ask him (doctor)?"
>
> Participant "No I didn't".
>
> Interviewer "And why do you think that was?"
>
> Participant "You are too frightened aren't you, of the truth really I think".
>
> (participant 5)

Participant 7 exhibited a *Fatalistic* adjustment where the diagnosis represents a relatively minor threat and there is no control that can be exerted over the situation. The participant exhibited an attitude of passive acceptance and active strategies towards fighting the cancer are absent:

> "I just felt I had some good friends and there is nothing I can do. I just thought, well it's up to the Lord above, whatever he wants of me, and I thought, I just did that, I said lots of prayers to him". (participant 7).

Participant 9 had very bad experiences with her GP and was admitted as an emergency. Her disease was advanced, and treatment palliative only. She appeared to look on her situation as hopeless. She was 82 and thus perhaps adopted a more realistic stance towards death than the younger women. But she spoke in terms of, "I feel as though there's little point. It's all been left until too late." (participant 9).

Greer & Watson (1987) describe this as *helplessness and hopelessness* adjustment as the diagnosis is seen as a major threat, loss or defeat. There is a belief that no control can be exerted over the situation and the perceived negative outcome is experienced, as if it has already happened and indeed participant 9 did view her life as over.

The final adjustment described by Greer & Watson (1987), is *anxious preoccupation* when much of the time is spent worrying about the disease coming back and any physical symptoms are identified as signs of new disease. All of the women displayed this in varying degrees. Participant 12 stated in interview that:

> "I have actually had backache, but I don't know if that's anything.....it could be muscular, it's certainly not ovarian cancer! I think it (pain) might be something, but I don't know what it could possibly be because there's nothing left in there now, is there?" (participant 12).

All women at time of interview had undergone six cycles of chemotherapy and were on a six monthly surveillance by oncologist and surgeon. Only two at the time of interview had been diagnosed with disease recurrence, and were awaiting further chemotherapy. All women expressed high anxiety levels prior to check up visits and admitted fears of 'something else being found'.

d. Theme 4 family/partner responses and interpretations

Responses to the disease from family were varied amongst all the women. Participant 1 went to the hospital alone for her fast track examination stating she didn't want to worry anyone and even though she never dreamt the diagnosis could be ovarian cancer, she did think it nevertheless may be a sinister result. On informing her husband and asked what his reaction was, she replied:

> "Oh typical man. Just tried to rationalise it and then didn't want to talk to me about it. He just wanted the hospital to deal with it and kept referring me to them every time I brought up a question. I suppose he was frightened and didn't want to talk about it. And then a couple of days later he broke his leg at work" (participant 1).

It was the broken leg that over took over everything, she stated that he was worrying about himself and how he would cope when she was in hospital as he now was unable to drive. She informed her colleagues at work about her diagnosis and they insisted she cut down her travelling. This initially annoyed her as she interpreted their response to her being unable to cope. Then she was angry because even though she was able to return home earlier from work, she then had to look after her husband and his broken leg. Her sister and mother came along to help with the house and teenage boys, and were very supportive pre and post operative. But discussing anything with her husband was viewed as taboo:

> "It (cancer) was taboo! If I brought it up or said I was worried he just dismissed it or got shirty. And he was absolutely no help around the house – the broken leg! I was furious" (participant 1).

The histology revealed she didn't need chemotherapy and she was so relieved. But when asked if her husband attended clinic with her to get the results:

> "Oh good grief no. He wouldn't put himself out, and quite honestly, I didn't ask him. I told him I was going, but he didn't offer to come, so I left it like that. When I told him the results he was really pleased, but more relief than anything else. He didn't say it but I know he was thinking, thank God, now lets forget all about it!" (participant 1).

When asked if she had looked ovarian cancer up on the web she replied that she had viewed a web site, but then became 'very scared' by what she was reading and abandoned it. But she did think her husband had looked it up, saying he seemed very knowledgeable about the subject when she came out of hospital. He denied looking anything up, telling her he only knew what information she told him. This is the only example where the disease created friction between the couple, all other participants reported the experience brought them closer together, or created a greater interdependence. One woman stated she had been amazed at her husband's ability to cope when it was her that normally did everything in the house.

The broken leg was obviously an issue, and without knowing the relationship before diagnosis, it is difficult to comment. There were teenage children and the information on the web can be devastating regarding prognosis and survival, therefore her husband could have been terrified at what information he had read. He did not attend clinics and so did not speak to the doctors on his own. Usually partners are interviewed by the doctor and given the opportunity to ask questions and have things explained. The broken leg prevented this and he also selected not to attend clinics with his wife post operatively. This meant she was 'furious' that she had been given this diagnosis, undergone surgery and yet on her return from hospital, he was still the focus of attention:

> "I was furious, but it didn't help. My mum and sister used to help, but he was hopeless. And I was desperate to get back to work, back to normal" (participant 1).

She appeared to displace her anger at the diagnosis onto him, especially when he broke his leg and it was him that needed looking after. She normally held down a very busy job, looked after the home and teenage children, and yet, the one time she saw herself as needing to be looked after, her husband 'failed' to conform. Her comment that she was desperate to get back to work, back to normal, was a way of putting everything behind her. Being back at work inferred being 'normal' and 'cured'.

Participant 2 found her partner very supportive, but her worries were centred more on her teenage girls. Her parents were dead, she was divorced from the children's father (he had disappeared out of their lives), and she had no siblings to help. Even though the new partner of a few years, was supportive and 'good' with the girls, she didn't know how he would cope on his own with them if anything 'happened' to her. He guessed something was physically wrong with her and urged her to make an appointment with the GP:

> "I just told the girls I had to go for tests, but P knew something was really wrong. He didn't say anything at the time, but later after the operation, he said he knew. He was trying to help but he got on my nerves. I must have been really horrible, couldn't be bothered with him" (participant 2).

Then when the diagnosis was made, her husband was:

> "Devastated, he was absolutely gutted. He'd looked it up on the computer at work and said it was bad. I still kept thinking and telling him it was going to be alright. But he's a worrier and I could see he was worried" (participant 2).

Later, whilst she was 'battling' with the reality of palliation, she still didn't share her worries with the family. She told them the surgery had removed the tumour and she was having chemotherapy 'just as a precaution':

> "No point in worrying them. They couldn't do anything and I couldn't bear seeing them upset" (participant 2).

By not discussing the truth with the family, she stated she was protecting them from the brutal reality. But she was still in denial regarding the diagnosis, and not admitting to the family was also a way of not having to accept and admit the prognosis herself.

The majority of women (N10) stated they thought their spouses had looked up the disease on the web. A minority of the husbands (N3) had discussed it with their wives, the majority (N7) didn't. Only 1 husband denied her diagnosis. She (participant 11) had been a participant at the breast clinic for twenty years with recurring breast lumps. All these proved to be clinically benign tumours and when these new ovarian cancer symptoms developed, he told her repeatedly it would be the same as the breast lumps and be benign. And throughout her surgery, he was very supportive but maintained the same stance. When she was invited to participate in this research, he asked her why she'd been contacted, she didn't have cancer.

Participant 3 found her husband looking on a website and said it frightened them both. She was twenty weeks pregnant when diagnosed:

> "It (Ovacome site) scared us to death, and we thought those must have been the worst women. But then the more I thought about it, I started to think about it, and I think having the baby made things a lot easier for us, and we're a lot younger. Some of those cases on the web were older women, and well, they're not as healthy as me. And you've got to be positive; having a young family makes you more positive. I said to my husband, they wouldn't have got through the surgery and chemo as well as me, and when you get older, well things have to be different" (participant 3).

Having a new baby and a four year old put a different perspective on the disease for this woman and she felt positive regarding survival at interview:

> "Oh yes I am very positive about the future, I know I'm going to beat it. I have this picture of P and me and the children growing up. Lots of people have bigger problems than me" (participant 3).

Denial, naivety or her strong religious faith gave her the support she needed. Other husbands didn't want to discuss it at all. They physically looked after their wives very well but rejected the offer of an interview with the consultant and oncology nurse. Their wives reported they didn't think their husbands had looked the disease up and didn't discuss it with them at all. They would take their wives for the chemotherapy sessions, sit and wait with them, but never ask any questions apart from solutions to minimise side effects etc. Disease progression etc. was never mentioned and they didn't wish to become involved in any interactions with other participants at the centre. Neither did they wish to meet the researcher during this research. Cups of tea arrived courtesy of the husbands, but they did not wish to engage in any conversation.

The husband of participant 6 attended each appointment with her and looked everything up on the web. She said he knew all about operation and chemotherapy but didn't discuss it with her. She chose not to know any more than the doctors told her, selective information. She commented:

> "But I think it's worse for someone like my husband looking on. I think if it happening to you, then you have to deal with it and get on with it" (participant 6).

This husband wanted to be involved with his wife's treatment and spent time discussing her progress with doctors and nurses. She thought he was feeling the strain:

> "After my operation he came in and I made him go to the doctors and they gave him some valium. He came in one night and he'd taken a valium and woken up and thought it was 5 in the morning and it was 5 in the afternoon! It had knocked him out totally for the day, but it was good because he was stressed. So I was looking after him as well in a way" (participant 6).

This participant stated their relationship had changed for the better following the experience they had both undergone. The woman had an ex-nurse as a friend and the participant had given her 'permission' to speak to her husband if he needed to talk:

> "He needed it, men do. I think the partner does need support as well as the person it is happening to" (participant 6).

Participant 11 did not want to know anything about the disease or prognosis. She actively avoided discussing it with nurses and doctors; indeed she physically left the consulting room, leaving her husband and doctor to discuss the results from her surgery. Whilst she was developing the symptoms of her disease (and trying to ignore them), she refused to discuss anything with her husband. She said he told her later that he knew things were wrong but left her to make the decisions. As her abdomen became more distended, he colluded with her to make special fasteners for her skirts rather than insisting she went for investigations to discover the reason for the swelling abdomen.

Also, he 'protected' her from hearing any 'truths' about the disease from MacMillan nurses visiting her at home. When the nurse advised the participant of available help for people suffering from terminal disease such as herself, her husband intervened and advised them such talk depressed his wife and not to speak about these things again. The participant stated she knew he had researched the disease on the web but she also recognised that this information was for his eyes only and not to be discussed with her. She had handed over total responsibility for her disease to her husband. He looked after her physically, spoke to the doctors *for* her and protected her from coming into contact with any 'dangerous' information. In addition, he researched the subject well in order he knew what he was dealing with, and ensured the subject was never openly discussed between them. There were boundaries that had been marked and accepted by this couple, and as she reported, it worked for them. Interestingly and perhaps surprisingly, she had agreed to participate in the research, however, during the interview she stated:

> "..I cannot be ill; I regard myself as not ill. I'm not into 'fighting it' and it's 'mind over matter' or anything like that. If I didn't have this problem here (pointing to her abdomen) I would be fine. I do not feel ill and there is no way I want to give the impression of being ill" (participant 11).

Participant 7 was very concerned how her having the chemotherapy made her husband so upset. She found coping with seeing him become distressed, very difficult and blamed herself:

> "By the sixth treatment in February I was so low I think.... my husband couldn't stay with me, it upset him too much" (participant 7).

An important theme that a number of the women (N8) reiterated was the one of guilt. In the initial questionnaires, several women mentioned feelings of guilt. Their responses highlighted how becoming ill, developing cancer, signified some form of failure, they were letting children, partners, parents down by 'succumbing' to this disease. Moorey & Greer (2002), discuss the guilty person concerned with apportioning blame as if an important rule has been violated and someone must be responsible.

However, the main difference here is that in attempting to explain *why* this thing has happened, the women blame themselves. They see it as a way of giving meaning to their experience (Moorey & Greer, 2002), and during this cognitive analysis, people with cancer often reason they have brought it on themselves or are being punished. Ideas of 'bringing it on the family' and making them unhappy are then targeted unfairly on themselves, rather than the disease. Several women demonstrated worries that they had made their husbands unhappy, several didn't tell grown up children about the diagnosis, because they did not want to worry them and felt guilty about interrupting their busy lives. This was something that should not have happened, something out of their control. Participant 13 spoke of 'It' the cancer, ruining her husbands retirement and holiday abroad. She felt guilty every time she had a bout of abdominal pain and tried to hide it from him as he'd worked so hard all his life and 'deserved' these later years to be peaceful and a time to do what he wanted. By developing cancer, she had 'ruined' it.

Participant 7 was admitted undiagnosed as an emergency to an assessment ward. She underwent abdominal and chest draining and was very ill for a few days until she was stabilised. She was informed on the ward that she had cancer and that it had spread to her lungs and so underwent surgery and chemotherapy. Yet she commented:

> "Yes they didn't have a (gynaecology) bed so I was on XXX for 4 days. Oh my god, I think it is so dreadful, I felt really dreadful for other people. There was a young fellow he must have been 18 or 19. Who wants a woman next to them at that age? It's not very kind is it? ....It's terminal really and they said this. It would be a miracle if I lived any length of time" (participant 7).

Her priorities were:

> "To see the family was alright. I know I had to keep on top because of them, because they are enjoying their jobs and everything and I didn't want to interrupt anything. I just felt I had to keep on top and get over this and live as normal a life as possible" (participant 7).

To all of the women, getting well, recovering was the main priority. But most stated the driving force behind this was in order they could return and look after their families, husbands and children. Hinton (1981) and Hughes (1987), discuss the burden that cancer places on relatives and participants and how despite the terrific strain it puts on relationships, some marriages do in fact improve following the experience. Changes in any part of the system, whether it's deterioration of in physical health or difference in the degree of support received, inevitably have effects on other factors. It is the way these are cognitively processed that determines psychological interpretation and reactions. These will now be explored.

e. Theme 5 psychological interpretations

These are the retrospective views of the women after they have completed their chemotherapy. The importance of the time factor is that they have time and opportunity to reflect and think about their experiences, and in some way, make sense of what has happened to them.

Participant 1, a senior manager, when asked about her early symptoms recognised them but managed to rationalise thus:

> "Backache, but had had a bad back for many years so attributed to that. Also had abdominal cramps and stress incontinence, but I was on diuretics and thought it was that. There had been pain on intercourse but I explained that by the erosion I'd had for some time and the cauterisation clinic" (participant 1).

She was a twin and reported that 4 years previously her twin sister had been diagnosed with uterine cancer. Thus it was at the back of her mind that the irregular bleeds she had experienced could be due to this, but she never 'dreamt' it could be ovarian cancer. On diagnosis at the clinic her initial thoughts were:

> "Stunned. I had no idea of what was really happening but I could tell by the women doctors' attitude that it was serious. They asked if I had anyone with me and I said I was on my own. I was still too shocked to ask any questions, it was still sinking in. Then they left me alone in this room and as I was lying on the bed, I felt my stomach and suddenly realised that it was hard and swollen. I hadn't noticed before.. really stupid" (participant 1).

Now a diagnosis had been made, she felt stupid she hadn't realised earlier that this was serious. The signs and symptoms had been there, but she had explained them away individually instead of looking at them as one big picture. She worked in the Health Sector and this 'feeling stupid' kept returning as an issue as if, as a health worker, she should have realised sooner and not 'allowed' these symptoms to have advanced so far. She stated her main concerns at his time were worrying about her two sons, 'what would happen to them if this thing was going to kill me?' And she also found difficulty in talking to people about it:

> "I had great difficulty telling colleagues at work about it and found it very traumatic - discussing it with them. They immediately tried to cut down my workload, and that made me feel angry as if I couldn't cope" (participant1).

This anger was also projected onto her husband when he broke his leg at work two days after her diagnosis. She was 'furious' with him, and even several months after the event, she was still angry at him. She spoke as if he'd done it deliberately. She had been given this shocking diagnosis and yet he had to break his leg and was physically incapacitated, unable to physically help her. Also because of her anger and/or his fear of her diagnosis, there was no psychological/emotional rapport or support for either of them. The participant effectively isolated him from her treatment journey and stated he was not interested in what was happening and 'wouldn't put himself' to come to clinics with her. But she commented on his knowledge of the disease and suspected he had done web searches whilst she was in hospital:

> "Oh just some things he said, seemed to be quite knowledgeable about it when I came out of hospital. When I commented on this he just denied it and said it was what I'd told him, but it wasn't" (participant 1).

Communication was a major problem with this couple. When the query was raised as to if the husbands fear of the diagnosis was a contributing factor to his passivity, she immediately refuted this, then thought about for a few moments and shrugged saying 'maybe, but he should have said'. This participant found great difficulty in coming to terms with her diagnosis and her displacement of this anger onto her husband's broken leg appeared not to mellow as the months went by.

Participant 2 expressed how frightened she was at diagnosis, but also relieved that something was going to be done at last. She realised it was very serious and was worried about leaving her daughters, if she was going to die. Perhaps because of this, she constantly reiterated she was going to 'beat it'. The oncologist's interpretation of palliation was never accepted:

> "(He said) no hope there, I don't believe that doctors can always know everything, you know. I mean you hear of people being told 'that's it', and the next thing they're cured. And how does he know that the chemo wasn't going to work, I hadn't even had any then!"(participant 2).

She distanced herself away from the oncologist but did speak to other staff:

> "She (oncology nurse) came and sat with me and told me what to expect. But the thing that really worried me was always the thought of the girls being left on their own. I'm not frightened of dying, don't get me wrong, I'm not going to let this thing get me yet, I could be run over by a bus tomorrow....I needed to get on, have the treatment and get on with my life"(participant 2).

She constantly spoke of herself as being a 'strong person' and 'coping well' and 'getting back to normal', and this drive was evident in the way she pushed herself through chemotherapy, organising a holiday in Canada a few months after completion. Twelve months after diagnosis, she was still refusing to accept the term palliation and insisted she was positive she had been cured. Her exclusions of the possibility of recurrence in her mind-set meant she kept herself very positive about the future. All her plans regarding work, relationships, the children and holidays were all very optimistic. She lived her life to the full and stated she never allowed any doubts to cloud her plans. These statements she made twelve months down her treatment trajectory, having had several positive responses from medical staff. She was convinced she'd beaten it. Recurrence, when it came, was brutal and she was dead within 8 months.

The opening statement from participant 4 was:

> "I have to admit in my case I felt 'I don't deserve this' and that is a very arrogant thing to say. And I don't think my husband deserved it after giving 14 years up of retirement ...and helping me look after my mum."(participant 4).

A retired headmistress, this woman transferred her mother from South Wales and moved her to live in their home for several years. The week she was diagnosed, her mother went into hospital and died. The participant expressed relief at not having to tell her mother that she had cancer, but felt it was very unjust that after all those years she and her husband had looked after her mother, something like this had to happen:

> "You always feel it's your fault because people always seem to think you have done too much or not listened to advice" (participant 4).

She considered herself a very calm person who planned and coped with things well. On reflection, she stated she was too preoccupied with her mother's death, the funeral and preparing things in the house, clearing away her mother's things, filling the freezer etc., ready for going into hospital, that she really didn't have time to think about the impending surgery. The 'I don't deserve it' concept was repeated several times throughout the interview, and when questioned about 'deserving' and 'non deserving' the participant went to great lengths to state she thought that no-one 'deserved' to get cancer. But she then listed the positive things she had actively engaged in eating sensibly, going to the gym, never smoking, drinking moderately and looking after her mother at home for so long. These, she had decided, were very valid reasons of why she should never have developed the cancer. It was suggested that certain people who smoke and drink all their life often don't develop cancer and she agreed. The moral essence still appeared to yield considerable influence over a genetic or environmental cause, and she reiterated that she had been 'good' and 'careful' and still fell victim. She also discussed the radiologist's response when she had the emergency scan:

> "I don't say he wasn't nice, but he just told me straight away and it was so unexpected. He also said it hasn't gone to your kidneys or your liver. They said I had a very large mass above the bladder…." (participant 4).

She revealed she was obviously worried, so much so that she phoned her GP immediately on returning home from the X-Ray. He referred her urgently and she was fast tracked to clinic. Following surgery, the consultant explained they had done many tests and found a few early cancer cells. Later, she then stated:

> "I spoke to someone and they said 'your results are with oncology' and then I was worried. I thought why are my results with oncology?" (participant 4).

She professed to understand and was very worried by what she was told when she had the X-Ray, understood her GP's explanation of the 'sinister' nature of the tumour, understood the consultant's explanation of finding cancer cells, and yet stated she was shocked that her notes were with oncology. And then comments about her husband:

> "He said 'you haven't got cancer', it's as if he is still denying you know" (participant 4).

And then followed this up with a direct question to me, as the interviewer, "I haven't really been ill with cancer, have I, he is right?"(participant 4).

This type of denial was also evident with participant 5. She had been visiting the GP for several months as her symptoms increased. Interestingly she stated she never saw the same GP twice. Each time she attended it was regarding a different symptom, excessive wind, diarrhoea, loss of appetite, increasing girth, stabbing pains in groin, backache, a lump in her groin. But she did not mention any of the previous symptoms to each new doctor, stating she assumed they would have a record of all her visits. This could also have been avoidance of confirmation from the GP, as by this time, she had already looked up ovarian cancer on the web (Linda Smith, the BBC comedienne had recently died of this and she had seen the publicity), and agreed that many of her symptoms were indeed very similar. She had also been visiting the GP for years on a regular basis, for checks as she had been on hormonal therapy (HRT), but again never mentioned any symptoms at these visits, as she considered they were separate issues. She explained her symptoms in safe terms. With her stomach swelling due to wind, because she had eaten something that disagreed with her. Loss of appetite, due to being bloated with wind and leaving no room for food. Tiredness as she was not eating enough food. Diarrhoea was due to unsuitable food and groin pain was muscular. On holiday abroad, she had been confined to her room, due to worsening symptoms and then went to a GP:

> "So when we came back I did go to the doctors and by then I had a *little* lump" (participant 5).

She was a petite person and when asked about her abdomen swelling:

> "It was huge, you would have thought I was expecting. It got bigger and bigger, so much I couldn't even fasten my trousers. I was having to wear pads because I was wetting myself all the time. It was unbelievable "(participant 5).

She was visiting the GP regularly, symptoms were increasing and she was never examined until her last visit, post holiday, when she was urgently referred to the hospital. But whilst she 'blamed' the doctors, she was also guilty of not actually giving them all the information at each visit, and she was very selective in the information she did impart. She dealt only in individual 'safe' areas, loss of appetite, tiredness etc. and accepted without question what she was told. The GP in return, she felt was telling her 'safe' information, it was muscular, nothing to worry about. When asked if following her web search, had she discussed her fears regarding the possibility of ovarian cancer with the GP, she answered:

> "No I didn't because every time I went I saw a different GP and thought they won't know what I'm talking about. I know they have notes, but perhaps if I had seen the same GP all the time..." (participant 5).

She was still working when she had access to the web, and several months passed prior to her going off sick (with the label of irritable bowel), going on holiday and then being examined by the GP. All this time her symptoms were increasing and she providing the GP with new signs and symptoms. She didn't discuss her condition with anyone, children, husband, and friends. So from the initial statements at the beginning of the interview where she denied ever thinking it could be cancer and stated she only 'twigged' when she saw the word 'oncology' on the nurse's badge, towards the end of the interview a different picture emerged. She found it easier to hide behind the label of 'ignorance' than to admit the fear and dread she was really experiencing. When she finally mentioned the lump and was examined:

> "Nobody mentioned at all that it could be cancer. He (GP) just said there is a mass there that shouldn't be there and they never really said, and even when I came for the ultrasound they never said. I know it sounds stupid, but it never even dawned on me" (participant 5).

On retrospect, she stated that she was too frightened of the truth, but now if anything similar occurred, she wouldn't hesitate on insisting to be examined by her GP. She then discussed at length her current symptoms and concerns, which she hadn't discussed with anyone else. She also went on to say, "I just really can't believe what I had and I just don't talk about it" (participant 5). She didn't discuss her illness with her husband and was unsure if he had looked it up anywhere. She knew he had been interviewed by the Consultant, but the content of the conversation was never discussed.

In contrast, participant 7 stated she had been thinking it was cancer for quite some time. An episode of vaginal bleeding was the impetus to visit her GP and at that first visit she asked him directly 'Is it cancer?' The confirmation of her diagnosis was a huge relief, as at last it was going to be dealt with:

> "It was just the confirmation of it. I had thought about it enough and then I was glad to know it was. It was the confirmation of it. The family were shocked" (participant 7).

Even though at this time she didn't know the prognosis, she felt a load had been taken off her shoulders. Now she could share her 'burden' with family, and even though the family were 'shocked' and 'devastated' at the news, she said at least it was a shared problem. Her prognosis was poor but she had adopted a very positive stance:

> "I think life does change because suddenly you have got something that could occur again, shorten your life or lengthen it or whatever. You don't know. Some people think of planning things, but I don't know, I haven't planned anything except going on holiday....it bothered me for a while it did, it upset me for a while. But I spoke with my family for the next few weeks, I felt that I could" (participant 7).

She looked on every month she was given as a bonus, was very positive about her wig and looking forward to joining a support group in order that she could help other people:

> "If I can help someone, I am lucky because I have got people around. But some people could be on their own with no support and this is why they need somebody" (participant 7).

The negative relationship that participants 8 and 9 had with their GP's impacted on their attitude to the rest of their treatment, and indeed lives. Sadly, both these women were not diagnosed until late stages, despite both attending their GP regularly with marked symptoms. Participant 8 had numerous problems apart from her health, her teenage daughter who was 'running wild', a husband who had recently left the army and was currently unemployed, and a house that needed much renovation. She appeared to engage in conflict in every relationship/situation she engaged in, and reported several rows she'd since experienced with GP's. She reported all the negative aspects of her stay in hospital, inadequate pain relief, and noisy wards. Despite the positive histopathology results that chemotherapy was not indicated, she commented, she still wondered if in fact she should have undergone a course of chemotherapy. She stated she would never trust doctors again.

Participant 9 was an older woman who felt very bitter towards the GP's because of her late diagnosis. Her results were poor and prognosis grim. In contrast to Participant 8, she reflected on her stay in hospital and chemotherapy, with positive attitude. But her life over the past two years, she felt was tainted by the relationship and treatment she had received from her GP practice. Her comments were that the experience had changed her attitude to life and people, and not for the better. Following diagnosis, she felt that family and friends had "disappeared into the woodwork", in case she asked for help. Her only advice to anyone in her situation would be, "Be prepared to stand on your own two feet" (participant 9).

Participant 11 arrived at interview with an A4 folder bulging with all the correspondence she'd received relating to her illness, including the envelopes with postage dates highlighted. She was a retired PA in a large corporate industry. She recognised her symptoms quite early on and was originally referred to another hospital for gynaecological opinion. After examining her and finding nothing:

> "What he actually said to me was, 'I am happy to leave things as they are now'. So I interpreted that as I was not in a terrible position at that moment, but should things get worse I would see him again. But it didn't, I was actually being signed off" (participant 11).

She returned to her GP a couple of months later with more pain and was told she had adhesions from an appendix operation fifty years previously:

> "I was quite passive up until then" and she returned to see another GP. This doctor did several investigations and rang the participant at home. "So when I went up I think she was expecting me to react, but I knew from the fact that she'd rung me up to say come up that she was not going to say it was good news. I knew I was really in trouble" (participant 11).

She then went in and had surgery and chemotherapy. During interview, she spent a great deal of time blaming the first hospital for not recognising her symptoms and delaying sending out her appointment. She had kept all the envelopes from the clinics with dates posted highlighted and related conversations (numerous) she had with appointment clerks. All her blame was on this consultant and none on the GP, despite visits on several occasions prior to referral. But throughout the session, she repeatedly stated "how stupid", that she had been "sitting back in awe" and not questioning the doctors. "Mistakenly I was reassured" was said several times, as she reflected and also blamed herself, for being so passive during the pre-diagnosis period. Her reflections on diagnosis are interesting. She commented from the first investigation results at the GP, that she thought she was "in trouble" and immediately post operatively, "I thought I had cancer", but when directly asked about her thoughts on diagnosis, she went to great lengths to talk of a "cyst" (and not cancer) and the surgeon not "*needing* to take the uterus away". Her reporting of the surgeon not removing the uterus during surgery was due to advanced disease. She had selected to construe this, as the surgeon viewing it as *unnecessary* to remove it, as it was not an important issue. She then pointedly stated:

> "But what I couldn't deal with is if someone had said 'you have three months, so it will give you plenty of time to sort your papers out'. I don't care about the papers, I can manage, I cannot be ill" (participant 11).

After her surgery, she reported that a Macmillan nurse had been to her house and thought she should 'face up to the problem', but she said that was not her way of coping at all and refused to enter into any dialogue. Her husband also supported her here and told the nurse not to depress his wife any more, with such 'negative talk'. An important issue that emerged was the disability allowance, the nurse informed the participant she was entitled to. This shocked her and she strongly disputed her eligibility for it. However, following discussions with the nurse that "wore me down"; she completed the forms and received the benefit. She called it the "slush fund" and refused to touch it. The allowance was paid into the bank monthly, the participant inferred that by spending it, she would have been admitting to qualifying for the disability label. Following her chemotherapy she pointedly asked the oncologist how she was doing. His response of "you are doing very well" was quoted verbatim. Her interpretation of this was that the treatment had worked and she was "cured". Thus a contact was immediately made with the benefit agency:

> "So I rang them up and said I have read the paper and the paragraph and am trying to comply with the conditions there. I have had the operation and I have had the chemotherapy and the person who is

> treating me has said I am doing very well and I really don't think I should get this allowance because I carry out functions of anyone who isn't disabled"(participant 11).

Following weeks of communication and more form filling, they finally told her she was still entitled to the allowance. She was devastated and commented it wasn't so much the money; it was more the agency stating she still was in need of it. She also refused the help of two community nurses and rejected the offer of a disabled parking badge for her car. This issue had a great impact on the participant and she pinned her hopes on the agency telling her she did not need the disability allowance. This deflection was as much of a priority, as the oncologist telling her she was 'cured'. Had the benefits agency taken her word, that she did not need the allowance, this would have been more 'evidence' of a cure; evidence weighed against the Macmillan nurse, community nurses and actual diagnosis.

4.5. Summary

The process of thematic analysis has identified and illustrated with textual examples of interviews important themes. The themes have highlighted signs and symptoms, experiences, interactions with others and psychological interpretations.

The cognitions, construction and interpretation of meaning for women with ovarian cancer are explored in depth in the next chapter which details the results of phase 2 of the research.

CHAPTER FIVE

Results Phase 2

5.1. Introduction

The results for the main research study phase 2 are presented in this chapter. The rationale for phase 2 is provided in chapter three.

5.2. Phase 2

Interpretive phenomenological analysis of interviews (IPA)

Table 5.1 details the superordinate themes that became evident via the analysis. Whilst individual women expressed several of these sub-themes, they did so in very different language and with very different inferences.

There were no predetermined categories and analysis produced six superordinate themes, with component subthemes. For example, the 'impact of diagnosis' meant very different things to each woman; and whilst several expressed initial fear or guilt, their perception and intention of these emotions were for entirely diverse reasons with totally different cognitive consequences. The subjective experience of the women interpreted through this idiopathic approach encouraged multiple interpretations, each with their unique meanings.

Table 5.1: Master table of themes

Superordinate themes	**Sub themes**
1. Impact of diagnosis of ovarian cancer	1.1 Denial 1.2 Fear 1.3 Powerlessness 1.4 Isolation 1.5 Refusal to accept
2. Self Identity	2.1 Losing face 2.2 Concern what others think 2.3 Denial of being different 2.4 Sense of failure 2.5 Loss of attractiveness
3. Self - partner/family	3.1 Sadness 3.2 Fear 3.3 Comparison with other family members who have had cancer and died/survived 3.4 Deflection 3.5 Anger and resentment
4. Coping Strategies	4.1 Positivity 4.2 Denial 4.3 Reassurance (with treatment and from medical staff) 4.4 Acceptance 4.5 Fatalism 4.6 Helplessness
5. Search for meaning – 'why me'?	5.1 Focus on normality –'good health' 5.2 Denial 5.3 Blame 5.4 Anger 5.5 Fatalism 5.6 Resentment
6. Future self; Transition from 'Old' to 'New' self	6.1 Sexuality 6.2 Normality 6.3 Return to wellness 6.4 Control of self and thus disease 6.5 Fear of recurrence 6.6 'Live for the moment'

Whilst the superordinate themes were evident in all cases, the sub themes highlighted different inferences and importance to each woman. These are discussed individually below.

5.2.1. Analysis participant 1

Self in denial

P1 was a 66-year-old retired woman, who enjoyed gardening and walking with her husband. She was very fit with no family history of breast or ovarian cancer. From her first symptom of post menopausal bleeding, there was a 6 month delay prior to visiting her GP. This interview took place when she was several months post surgery and nearing the end of her chemotherapy; thus she had considerable time in which to reflect on her experiences and construct how this had impacted on her 'old self' and how it would influence her 'new self':

> *Int.* What were your early signs and symptoms?
> *P1* Well I think this is with ovarian cancer, you don't get any. The only thing I had was, you couldn't even say it was bleeding, it was spotting....I really could not believe there was anything wrong, well not seriously. There had been some spotting but it was only one month, a few days in one month and that I was sort of dismissing as something very minor really. Thankfully I did go. (p1 para 1-2)

P1 justified her 'good health' during these 'symptom months' (i.e. the months following abnormal bleeding prior to consulting the doctor) describing strenuous walks and challenging gardening, digging up lilac trees single handed etc., in an attempt to justify or explain her reasons as to why she couldn't have been ill/ didn't seek advice from GP. But she does hint at feeling worried, stating she didn't think anything was wrong, well not *seriously* wrong. Thus she was aware of bleeding that shouldn't be happening but was waiting for another symptom to substantiate that something was amiss. She also discusses that the GP 'did a *sort* of examination' but couldn't tell her anything, i.e. P1 had been right in her actions of not going earlier, as when she did visit the GP, nothing was immediately diagnosed and she had to be referred for further tests, i.e. P1 suggested, there was nothing obvious which was detected by the GP. She recounts:

> *P1* I went for a scan, the type they look on a screen, internal. And they said they could see a mass, they did not go any further; it might be fatty tissue, they did not alert me too much to anything and then I had the CT scan........
>
> *Int* So when you had the spotting, what did you think yourself it could be?
>
> *P1* I don't know really. As I say because I had no other symptoms I just thought I would leave it and see if comes next month and see if I have something else to go on. But it didn't come again and so in a way I dismissed it and didn't go the next month, and so I suppose I just thought there is nothing there, and I should have gone.
>
> *Int* How long was it after the spotting you actually went to the GP?
>
> *P1* It was about 6 months to be honest. Nothing else occurred and I felt so well. The things we had done in the summer, I thought there is nothing wrong; I would have something else if there was something wrong.
>
> (p1 para 2-4)

P1 visits her doctor who does examine her and is concerned enough to fast track her to the hospital where she has a Trans Vaginal Scan and physical examination and is then referred further for a CT scan. During all of this she is in denial and states until she sees the consultant a month later, she never even thought it may be cancer. This is interesting as most patients who are told they have a 'mass' immediately suspect cancer even if it is benign. Participant 1 had a son diagnosed with cancer four years previously, this had created emotional upheaval in the family. Thus for P1, with the memory of her son's illness, it would have been very strange if she hadn't thought about cancer. More probably, she was internalising these memories and experiences and applying them to her own state of health. By not externalising her thoughts, sharing them with anyone, there was an element of protecting herself and also her son who had been through his own difficult and stressful period. Her real world constructions that she was attempting to superimpose as dominant, were those of normality. When in reality the underlying 'truth' was that she was experiencing feelings of uncertainty. In the light of her son's experience, she was also very afraid of the consequences. Her denial was a way of coping, "it's only one incidence of spotting, if it was serious, something else would have occurred".

She went into detailed descriptions to demonstrate her fitness prior to diagnosis, i.e. strenuous gardening, digging up a tree on her own, and long walks she'd undertaken with her husband. All these examples are attempting to confirm her declarations that she was symptomless, and secondly, that she was not worried. After all, if she admitted to being worried the sensible next step would have been to seek help. Also this disease was advanced on diagnosis and P1 was aware of this. So there is also the underlying assumption that if she had gone earlier it may have been caught at an earlier stage. Here she risks introducing and accepting the element of self blame if she openly admits she was aware something was wrong and also that she did nothing about it. She does actually state:

> Yes, I did if you like, have a concern in that because I didn't go to the doctors straight away after the bleeding how it had then progressed because I had left it.
> (P9 para 55)

This suggests she had been thinking along these lines, and admits she 'had left it', and also the use of 'concern' suggest she had been mulling it over.
When asked what the decisive factor was in making her eventually seek help, she states:

> P1 But then it was one of my cousins, an older cousin than me, she is 15 years older; and she said she was going to the hospital as she had had some bleeding, and I thought I really ought to

> see the doctor. There is probably nothing wrong, but I had better go. That sort of prompted me if you like, to go.
>
> Int You saw your GP then and he referred you for a scan?
>
> P1 I have the dates and everything from when I first went to the doctor. I first went to the doctor on 31st August and then I saw the lady doctor on 5th September and then I went for the scan on 12th September, and then I had the CT scan on 19th September. I went to see consultant on 24th September and he gave me the results. It was devastating when he said what it was and that I would need chemotherapy, you know, I just could not believe. (P1 para 5-6)

P1 was poised and just needed a trigger and this came when her cousin mentioned her own bleeding followed up by her actions, i.e. going to see the Consultant. P1 is still denying she really needs to go, after all 'it's probably nothing' but the unease she is feeling is now great enough to prompt her to act. She listens and is alerted to the fact that a similar symptom in her cousin had been reviewed by the GP and thought serious enough to be referred to the consultant at the hospital. This must have initiated concern with and initiated a GP appointment.

The feelings of devastation suggest this was probably confirmation of her fears; cognitively this woman was dealing with feelings of denial, conflict emerged when the consultant informed her of advanced ovarian cancer of which she knew nothing, with subsequent referral for major surgery and chemotherapy. This information led to internal conflict and cognitive dissonance, as she had not prepared herself for such a diagnosis. Her focus on all the dates and appointments suggests a deflection on the *reasons* for these appointments. She had everything organised and remembered all dates and times. When I discussed with her what was thinking about during this period of testing and referrals she replied:

> *P1*....Well I thought it might be a hysterectomy. But I did not think it would be cancer. Cancer had not occurred to me. I thought it might be a hysterectomy because it was bleeding.
> (P2 para7)

Again she insists cancer never entered her head, and interestingly admits she was thinking of hysterectomy but doesn't give a reason for having to have one:

> Int So why go to the doctors?
> P1 Yes so it was just my cousin saying about this really.
> Int How did you feel once you had been to the doctors?
> P1 I thought I had done the right thing, I thought I have done the right thing, and if there is nothing wrong it doesn't matter and you don't say to everybody straight away, because if there's nothing wrong you don't tell people. So I went and at the church again it was Harvest Lunch and so the ones that are on the committee, I did just say to them, I have got to go to the hospital because I have had a bit of spotting and one of the ladies said, 'Oh I had that before R got married and I thought I must go, but it was nothing, just fatty tissue, nothing, oh you will be fine'.
> (P9 para 63-64)

There is an element of relief expressed here, she knew she had 'done the right thing', emphasised by repeating the phrase. P1 also expresses concern that people don't know what her diagnosis is until confirmed; perhaps fear of looking silly or being labelled a worrier. But yet she does confide in the women at church once she has her appointment through, although she does omit to say the spotting was 6 months ago. She is seeking reassurance; now she has faced going to the GP and has commenced the diagnosis/treatment journey, she is concerned, or perhaps resigned about what is going to be found. When asked if she was worried at this time, she responds:

> P1 Well no, because it had been happening to me I accepted it. My son had cancer 4 years ago, he had Hodgkin's and when it

> happened to him I just went to pieces because it was our son. He had just had a baby daughter and he was diagnosed and still on paternity leave, and it was just awful. But when it happened to me I could cope with it. I think 'it is me' and I have got to get on with it, and I have.
> (P2 para 8)

Comparing the alarming time with her son when she 'went to pieces', she rationalises nothing can be as bad as that and states she just has to get on with it. She also realises there are few options and she has little choice on decisions that are made by doctors, but throughout the interview she demonstrates she is willing to acknowledge their decision making, accepting what she is told without query; Throughout her treatment she shows a willingness to do whatever she is told without raising any issue:

> Int Did you look up on the web to look for more information?
> P1 Not really, they gave me a lot of information when I went to Liverpool Hospital and so I brought everything down (stairs) and read those booklets and so realised before the operation how it could have spread. I did not know what the spread was, but they knew it was cancer because of the blood results I had taken at the hospital and the scans. But what stage, because they said there were different stages and the vital organs... So that was anxious not knowing how far it had spread. I only took information from the books.
> Int What about your husband, did he look up any more?
> P1 No, no we thought what ever is to be will be and that we couldn't change it you know, and so we would cope as we went along.
> (P2 para 10-12)

There is an element of fatalism here, 'what ever is to be will be', feelings of hopelessness, and things way out control. P1 denied looking on the web for information about a disease she had just been diagnosed *with*, and also admitted knowing *nothing* about, which was interesting especially as she later admitted looking on the web to find out all about wigs. When asked directly about this she laughed but was insistent and stated:

> P1 No, as I said I had all the books and they were very informative and so I read up on that. That is all aspects as well you know relationships.
> Int Was there a reason you didn't look it up on the web?
> P1 Yes because I think, I just thought everyone would be different. I don't know. I just didn't.
> (P7 para 37-38)

The element of fatalism interweaved with protectionism, whatever happens is out of my control is a theme that underpins the cognitive psychological constructions of participant 1. This woman believes that the doctors are in control, as they know what is happening; the clinical and biological information is their area of expertise and she feels that she does not need to know. She cannot alter what is going to happen, therefore she has decided to detach herself from clinical reality and cope with what she feels able to control. This strategy, for her avoids emotional disequilibrium.

She will address 'safe' issues in the literature she has been given; she will not seek help or information from MacMillan nurses or any other source as these may be too emotionally damaging. When asked the reason for not looking on the web she was evasive stating she thought everyone was different therefore it wouldn't apply to her. But this opinion, 'everyone is different' would also apply to the books she was reading. Then she closes the statement with 'I don't know', suggesting, I'm not going there, I don't want to discuss it, closed door. She had actually brought all the books down and laid them on the table, inviting the interviewer to have a look at them. When asked if her husband had read them she replied:

> P1 I don't think he read all of them no. I left them out on the bed and it was up to him if he wanted to or not, because I did not

> want to push it. Again after seeing Mr H, you saw a MacMillan nurse so they were always on hand if there was anything you wanted to discuss or ask them. And so it was there for you if you wanted it which some people could well have done. ...But I just felt with the family I have got, I was not alone and so I was alright.
> (p14 para 85)

Safety barriers have been set up, P1 is selective in the information she absorbs and deals only with what she can cope with. By her leaving the books lying on the bed and not knowing if her husband has read them, suggests there has been little generated discussion, with both parties recognising safety in silence. P1 leaves the information out and is making an unspoken statement, read them if you wish but don't discuss with me. She reiterates this sentiment regarding the MacMillan nurses at clinic, their kind offer is there but she rejects it; they may say things she doesn't want to hear; and she has a family who respects her boundaries i.e. who will not engage in dangerous talk. She also talks about the discharge letter to the GP, now routinely copied to the patient, and even though she doesn't understand the terminology and thus most of the content, she states she is pleased she had it:

> *P1* I didn't have to have it (the letter) but if you want it and it is new, they don't hound you at all.
> *Int* It is new and lets patients know exactly what is going on.
> *P1* And that has gone to my doctor hasn't it?
> *Int* Yes that's right
> *P1* I thought if I go to the doctors, I won't take it in. Well you can't can you, it is too much to absorb? Even though I may not understand all the terminology, it gives me a good idea of what has happened.
> *Int* And do you understand the terminology?
> *P1* Well maybe not all of it. But it (cancer) had got a hold and well I don't know. He said it would have spread; it was that sort of diseased. I don't know if that was the same?

> *Int* Have you thought about taking that to your doctor and having a chat with him, or do you feel you know enough?
> *P1* I think so. With them saying that the CT scan I had before the chemotherapy did not show any signs of cells....We did say when we went to see Mr H afterwards 'how do you know it hasn't spread?' He said it's because.....I forget what it was, but he reassured us that they could tell from the slices, whatever they do with the biopsy.
> (P14 paras 86-92)

Her comment that even though she doesn't understand most of the content of the letter, she has no intention of taking it to someone who would interpret it for her i.e. her GP, gives insight into her denial. She says she is pleased to have the letter because it gives her an idea of what has gone on, and acknowledges the report states that the disease was advanced. But she doesn't want to know any more and prefers to cling to previous positive verbal comments relating to her CT scan prior to her chemotherapy rather than learn more about her up to date discharge information. There is the underlying assumption by P1, that even though she does not understand most of the content of the letter, things must be alright or they wouldn't have sent it to her.

This refusal to accept details is also highlighted in the conversation she and her husband had with the consultant, following surgery. She states that "we' asked directly for information regarding spread of disease", which was a considerable question for P1 to be asking outright. She admits she 'forgot' the response from the consultant, apart from his 'reassurance' that he was able to tell from the biopsy. The Patient 1's state of denial was so strong that she probably found it easier to shut off from his answer, hear only what the 'acceptable' and positive responses were.

One interesting point that P1 raised was how astute she now was regarding signs and symptoms and any changes in her body. She was discussing her chemotherapy and the bad experience of the first session; she produced a hand drawn chart with common symptoms experienced during chemotherapy detailed along the top, and ticks or crosses relating to her own symptoms:

> Int How do you look upon your health now since having this....How about any aches or pains?
> P1 No I don't seem to have anything. Lets see what I had, I have my little chart, my colour coded chart.
> Int That's excellent. Who decided to do that?
> P1 Me!
> Int Oh good. And what was the reason behind that?
> P1 Just to remind me when I had different things in different weeks, and to see if it followed a pattern.
> Int Right.
> P1 Then I know what the pattern will be.
> (P 7 para 40-44)

Here is a woman who has been engaging in reflection on signs and symptoms and listening to her body. Perhaps she feels the consequences of ignoring the initial spotting for 6 months were great indeed, and she now intends to make notes of everything that happens to her. Having chemotherapy can be pretty traumatic physically and psychologically, but P1 lists all her experiences, which are not trivial, but verbally she minimises the effects of most of them, even losing her hair and having shingles:

> P1 Well again I feel so well again, just like I did before I had the operation, it is as though I have only had the operation, it is as though I have only had the operation. I know I have had some symptoms from the chemotherapy but nothing that lasted......I just feel normal really again.
> (p7 Para 40)

Her priority and driving force now was to get back to normal.

The Positive self

Denial as a psychological strategy worked well for P1, but she also needed an alternative support system, and this she created with her positive self. Being positive compliments denial well; she internally denies the cancer is terminal because she can externalise and demonstrate she is feeling well, back to 'normal', her disease free state. From the beginning of the interview she emphasised her excellent state of health, which was an undoubted positive factor which helped her through surgery and chemotherapy. She also spoke of her support groups at the Church and her family, and here her faith and close family network were tantamount in boosting the positive aspects of her social and psychological constructions. They made her feel good and gave her hope and she used this psychological tool of positive thinking to eliminate, or at least limit the fear and uncertainty she was experiencing:

> Int Do you think what happened to your son had a reflection on how you coped?
>
> P1 I always say he is my shining star because he coped wonderfully with it, with his circumstances you know of having a baby, and he got through it, so yes knowing how he coped. It is easier when it is yourself. Other people have been more worried for me than I have been for myself. I have been concerned but I think other people were more worried for me.
>
> (P2 para 9)

Here P1 reflects on her son's plight, young with a new baby and having to endure chemotherapy and radiotherapy. And he came through. Therefore as she doesn't have such responsibilities, quite the reverse in fact, she has many people who are willing to look after her, take away all responsibilities and she feels secure with her support networks. She has physical, emotional and spiritual support and these are her psychological safeguards:

> *P1* I just thought we have got a close family and I go to the Church and the support, the post cards, I got over a hundred cards. You are just surrounded by people who are concerned

> about you. I did not feel I needed to discuss it with anybody outside the family. I was alright.
>
> *Int* Did you feel it helped actually talking to people about it?
>
> *P1* Well I didn't sort of go into detail about it. They just knew that I had ovarian cancer and I would have to have follow -up chemotherapy, and no I did not go into detail. In a way I feel you are trying to make out you are on deaths door and I did not want to think that. I just wanted to have a positive attitude and so I didn't go into worrying detail with anybody.
>
> (P3 para 13-15)

Here P1 verbalises her thought patterns quite succinctly. She acknowledges and welcomes her support groups but she has minimised the amount of information she gives them. This is a safety factor, people are less likely to ask 'awkward' questions about her disease when she has made it quite clear she doesn't want to talk about it. She talks of 'deaths door' something she has obviously thought of but refuses to accept, and thus avoids 'worrying details' ever being introduced into conversation. The positive attitude is all important and she needs her support group to follow suit. She talks openly about chemotherapy and even invites friends and relatives to accompany her to her sessions. But this is quite safe subject matter as she has lots of divertive subjects which deflect attention away from the *reason* of the chemotherapy- her hair loss and wig, her side effects and the other patients:

> P1 Yes and I meant we did read the books they give you and I knew I would lose my hair and all this. And in one of the books it says 'look good, feel good' and that is what I have gone by, 'look good, feel' good and it has helped.
>
> (P3 para 17)

Focus on the wig was a big issue to help her look normal, 'I didn't want people to notice'. She was organised well in advance before her chemotherapy started, and had the wig ready to wear as she lost her hair. She looked it up on the website and travelled across to Liverpool for a fitting. These diversions enabled her to focus on the positive aspects of the treatment journey and recreating her 'normal' appearance:

> P1 And again as I say, I just want to, this feel good look good factor. Because the others that go in, you know they wear the scarves and one had a big woolly hat on and you think they are not doing themselves any favours you know..... I just want to look normal; if anybody sees me I look normal.
> Int Why do you think women don't bother with a wig?
> P1 I don't know. I don't know whether they want people to know they are chemotherapy patients. I don't know but to me it just draws attention to them....and I thought In couldn't walk around like that, and as I say, even when I put a scarf on I look ill and I don't want to look ill.
> (P 17 para 104, 111, 112)

Here P1 is explicitly stating she doesn't want to appear anything but normal and certainly not as a chemotherapy patient. She is fighting against the 'ill patient' role and doesn't agree with, or profess to understand the women who don't wear wigs. This essence of normalcy underpins everything P1 is attempting to achieve, and looking normal to P1 is making the statement, she *is* normal. P1 was impressed and used as her model, 'the look good, feel good' factor and out of everything she read in the books, this was the one most important model she found helped her through this ordeal.

When asked if she talked with any other patients during chemotherapy, or compared herself to them, she was slightly evasive stating it was difficult to talk because people have friends with them and the bays are far apart. But socialising with other patients in a chemotherapy setting would be dangerous for P1, as patients are more likely to discuss and compare disease stages and treatment etc. and her avoidance/denial state would not sit happily with such involved discussions. But she does mention one woman:

> Int Have you got to know any of the patients there?

> P1 There is only one who has been on the same Monday.....but she said she opted first for tablets.....it (cancer) has recurred so the tablets obviously didn't clear it and so she was back in having the same as me, Taxol.
>
> Int Right.
>
> P1 And she was younger than me, she said she was 53. And so I am glad they didn't give me an option which is nice you know, because the first time on the tablets, she didn't lose her hair. And whether she thought maybe being younger, I don't know, maybe she went for that first and then it recurred.
>
> Int Yes, you think perhaps she made the wrong decision?
>
> P1 Yes, I don't know, but she is the only one. There have been others ... but you are quite away across the room from people; it's difficult to have a conversation.
>
> (p16 para 98-101)

P1 has obviously compared this woman's treatment to her own, and sees tablets not being the best option. Without clinical background it is difficult to make any accurate judgement, but P1 categorises the differences between herself and the woman- she's younger, didn't lose her hair and she had tablets which P1 thinks weren't as strong. Thus she rationalises those were the reasons the disease recurred. She cites her own regime as:

> It is strong. It is a full day; it is a 3 hour bag of Taxol which is a strong one and an hour's bag of another. I am usually there from 9 to 5.
>
> (P4 para 18)

The woman is justifying that her treatment was severe and intense, so much so that she lost her hair after the first treatment. She sees it as the best treatment and she will be cured. She also talks about her scan and that the oncologist stated that she did not need a mid-treatment scan. This reinforced her positive outlook as other women needed mid-treatment scans but she did not:

> P1 During my second visit at C I saw Dr X who is the head oncologist and he said 'next week I am going to book you in for a scan'. He was looking through my notes and he said, 'oh no, there is no need because your first scan was clear'. When I went this week it was a different oncologist and I brought it up and said maybe another scan at the end. And he said 'I don't think that will be necessary because there was nothing to show on your scan at the start'... I just feel positive that Mr X did a wonderful job.
> (P5 para 30)

The emphasis here is on opinions from the 'head oncologist' which is then checked at a later date with another oncologist, who again reinforces the positive scan outcomes. P1 sees her not needing a scan because the surgeon did such a wonderful job removing the cancer. She reports that other women check with her about repeat scans, but she is the only one who doesn't need one and this again gives her huge reassurance and reinforces her positive stance.

When asked what advice she would give to another woman just diagnosed with ovarian cancer, her responses are interesting:

> P1 I would tell her to be positive I think, that it is not too frightening as it may be sounds. You know if it caught early then, I don't know. I don't know, if, when I go back they will say well, obviously they do regular check ups, but I don't think it is going to be one of those things where they will say ' well you have got another two years'. I think if I just keep going back for checkups it could be something else that kills you in the end. You are not here forever.
> (P 18 para 113)

This woman commences with positive advice, suggesting the whole experience for her was not too frightening; she coped well with the long and difficult process. However, she then makes a statement regarding early diagnosis, and the tone changes. Instead of advice giving, it becomes a monologue relating to her personal concerns. She reveals her fears more openly than earlier in the interview and relates to the check-ups and fears of possibly having limited time left, implies further treatment could kill her and that she has no one to support her.

There is little evidence of P1's positive attitude in this last paragraph, instead it hints at all the fears she holds about the future. Her carefully created constructionist framework, combining denial and positivism, worked well to protect P1 as long as she managed to retain it intact. These last statements demonstrate how near the surface her real fears lingered, and what a lonely journey her 'constructed reality' was for her. She did indeed have a terrific amount of support from friends and family, but this was external and superficial and all within the boundaries and rules set by P1. The daily life reality of P1 was very private and one which she effectively concealed from everyone. She constructed her own protective mechanisms in order to cope with these traumatic events. For P1 this worked well and gave her strength and ability to deal with this terrifying experience most of the time.

5.2.2. Analysis participant 2

P2 was a 52 year old professional woman who had seen a paternal grandmother die from ovarian cancer, thus she was aware of signs and symptoms of the disease. Yet she waited for over 6 months from her first indicative, and on reflection, obvious signs of the cancer, before she contacted her GP. She was a married woman with two teenage girls and had close encounters with the realities of terminal cancer with her father and recurrent disease in a friend. During her treatment, her husband also became ill with a suspected diagnosis of cancer.

The 'denial self'

> *Int* When did you actually notice any signs and symptoms?

> *P2* 'Probably I noticed a few signs about six months before I was diagnosed but I thought they were bits and pieces going on because I was going through the menopause. I just put it down to that and stress.'
>
> *Int* What kind of symptoms were they?
>
> *P2* I was bloating, I had backache and heartburn. Because I was already menopausal, I didn't have the signs of periods because I wasn't having any and so that wasn't the indicator. But it was those sorts of things, feeling very tired, but I just put it down to going through the menopause.
>
> *Int.* And so what was it that made you go to the doctor?
>
> *P2* It was frequency of needing to do to the toilet and that was becoming, I thought, a water infection. I was drinking lots of water and then also I was very bloated, my stomach, and K thought it was a joke that I looked like I was pregnant, and I said ' well don't laugh, it would be a miracle'! And my mum also looked at me and said 'stand up straight ' and I said 'I am' and she said 'you're a funny shape' and I thought this isn't right and so I went. But I thought it was going to be a water infection.
>
> *Int* But what about the swelling?
>
> *P3* I think I put that down, I thought maybe I'd put on weight. I didn't connect. My paternal grandmother had ovarian cancer and so I did know about it, but I never connected that. It was quite a shock.
>
> (P1 para 1-4)

This woman gave all the classic signs and symptoms and with family insight into the disease, she still denied anything serious was wrong, attributing her symptoms to urine infection, putting on weight etc. Even when the weight was specifically noticeable around her stomach area she still explained it away:

> *P2* There was a dress I had bought and I kept going to put it on and I can remember standing there saying to my daughter 'Oh I don't know why I have bought this because every time I have put

> it on I don't wear it because it shows my belly off'. My daughter said 'yes you look pregnant' and laughed. I would take my dress off.
>
> (P10 para 51)

Thus P2 was very aware of her changing shape, probably for about 6 months. This discussing with her daughter and husband and then joking about it, almost sounds like collusion. Was she testing them? She was aware of her grandmother's diagnosis, saw this growing tummy and asked opinion from the family in a joking manner. They continued to laugh about it, thus if they didn't think it was serious, why should she? It was only when her mother pointedly commented on her not looking right, that P2 took it seriously and decided to visit the doctor. On reflection, she discusses being on holiday the previous year and feeling sick the whole time and putting it down to 'heat, salty water, food and being tired'. She recognised things weren't right and was making excuses for every symptom. She even reports going to the toilet 'and it hurting. I felt really odd and I thought 'that's weird; I will have to drink more water'.

This refusal to accept anything was seriously wrong was effected up to the time until her GP stated she was fast tracking her. Immediately this denial/refusal state evolves into anger and blame at herself for not recognising symptoms earlier:

> *Int* So what were you thinking then?
>
> *P2* I thought I had cancer. OK ovarian cysts were being talked about but this was rather large and I ended up thinking 'why didn't I go earlier?' I should have gone before, I should have picked these things up, I should have taken more notice of my body
>
> *Int.* Did you think back to your Grandma, did you link it?
>
> *P2.* I did link it yes, but my mum had linked it for me very early on actually! So yes although my gran was in her seventies and yes I did obviously think about that......

> *Int* So what did you know about ovarian cancer?
>
> *P2* The silent killer and so I did know that if it was that, it could be really serious and it could have been terminal possibly. So initially when the thoughts were that it was, it was a bit scary because I was aware that it is. Because by the time I got there, and I was a classic case and I knew.
>
> (P2 paras 7-10)

So here the diagnosis looks grim and P2 starts linking all the signs and symptoms together and realizing how long it has all been going on. She makes the connection with her grandmother and reflects upon the months leading up to diagnosis. She states quite explicitly that she was 'a classic case' suggesting she knew exactly all the signs and symptoms:

> P2 I felt stupid, I felt really silly as well.....and I did feel silly because I convey myself as a pretty intelligent person. But life events go on, I couldn't say I was being ill. I wasn't well at times, but I was a full time teacher working etc., etc., and I put it down to those things.
>
> (p2 para 11)

Diagnosis is made and P2 sees with clarity all the signs she's been explaining away, and is very concerned that it could have cost her life. The tumour weighed 2 1/2 Kilograms and the consultant informed her it had probably been growing for 18 months. She explains this during interview, and also perhaps to herself, by saying she has large hips and thus her pelvis would have accommodated this tumour much more so than in a smaller woman. But she had already stated that her obvious growing tumour had been discussed by all the family, and well recognised by herself. The seriousness is recognised as she admits her anger at not going sooner:

> *P2* At the time particularly until I had the op, I was very easily beating myself up that I could have prevented possibly.....I had lost my dad a few years earlier to cancer and so that was not a

> very good thought. Then I thought I can't keep doing that, this is how it is, I have now got to go with whatever is going to happen and try the best to get myself well.
> (p3 para 14)

Here P2 recognises there's no point in dwelling on what *should* have happened, or what she sees as what she *should* have done, and makes a change in mind set from guilt to being constructive and positive. She reflected upon the negative aspects and the worst scenario, remembering the death of her father from cancer, a situation she was closely involved with, and looks to the future, intent on making the most of getting back to normal, regaining her wellness. Several times throughout the interview she describes herself as a strong, positive woman, and thus having 'allowed' this disease to get so advanced, she sees it as her responsibility to get on and get it cured. She refuses to allow negativity in and on reflection, was very positive about 'beating it'.

The 'Protecting self'

P2 also set up safety boundaries for herself regarding discussing cancer. Knowing the realities of cancer and with her father and grandmother's deaths in mind, she attempts to distance her own diagnosis from theirs. She talks of 'cysts' rather than cancer, seeing that as a safer diagnosis:

> Int Did you look it up on the web?
> P3 We actually looked up ovarian cysts because that's what I knew I'd had....obviously there was a little bit about cancer and I did look that up and I read that and I read the symptoms and things and I thought, 'yes it does fit' but I didn't do too much.
> (P4 para 18)

She then goes on to say she was 'quite careful with the sites I looked at' and also that there were some 'pretty good ones as well' i.e. optimistic rather than pessimistic. P2's fear of cancer and all that is associated with it is evident in her statements. She had helped look after her father at home whilst he was dying with cancer and she knew the disease outcome of her grandmother. She had witnessed what cancer could do; she didn't want to read any more frightening things that may indicate her case to be even more serious. She states she did read about the symptoms but didn't 'do too much', i.e. she saw what she considered she could deal with without being too frightened. She also dealt with things in stages, i.e. selectively compartmentalised knowledge as it came through. Each drip of new information she dealt with carefully 'this bit, the next bit, out the other end'. This segmented journey she could cope with, assimilating and getting used to each little development rather than looking it all up at once. When her initial fears were being realised, she relates being told the news by the consultant:

> *P2* He realised there was a huge cyst going on and it could be cancerous and whilst he didn't scare me, he didn't hold that back. I felt he was very calm and rational about it and I was now in that league and I just had to trust him...
> (P4 para 21)

To P2 'Cyst' didn't have the same connotations as cancer, it sounds benign, less threatening, removable, and more importantly, curable. 'I think it's the 'cancer' word isn't it?' (para 27). Thus in selecting to use this 'cyst' term she was externalising her desires and hopes that her outcome was going as favourable as if her tumour was a cyst. Nevertheless, as a contradiction she also appears resigned to the diagnosis and states she was 'now in that league' i.e. the cancer league; she was a marked woman, preparing for a fight to win, and all being a cancer victim entails. When asked if she discussed her diagnosis with friends she admitted she had:

> *P2* I did a bit, yes, a couple in particular. One very good friend actually has been through breast cancer twice and so there was a bit there, but I think we were quite careful with each other.
> (P5 para 26)

'Being careful' is interesting and certainly implies establishing safe boundaries of discussion for both of them. P2 knew exactly what she considered 'safe', what she was prepared to discuss and in return, what information she wanted to receive. This friend had 'gone through' breast cancer, recovered and then suffered recurrence. This was something in P2's mind and she certainly didn't want to be receiving too much information in this area. She cites the friend had looked up breast cancer on the web and "got herself in a right tiz" and became very worried. Following this example, and using this as an excuse, P2 stated, "I just said look at the moment, if they tell me it is that, I will look more and find out". She had watched her friend scare herself and knowing how she was feeling herself, decided to be very selective in what she looked up and discussed with friends. She also used this friend as an example and excuse not to search things out, the friend had got herself in a state and P2 did not want to do that. No good had come out of discussing and looking on the web, so what was the point? She commented they gave each other support "in a sort of unspoken way". A safe way where each could retain their own thoughts and beliefs unchallenged. They had established safe boundaries for each other, and even though each cancer and treatment was entirely different for each woman, the underlying outcome they saw as potentially the same. She also was very concerned about protecting her daughters who were early teens:

> *P2* The older one realised straight away without me saying. She said 'it could be cancer couldn't it?' and the younger I think is in denial. She couldn't cope with mum being unwell and so she cuts it off really. When we talked about the fact of it being cancer she was like 'what are you talking about'? She found the whole thing difficult, she very much went into a little world of her own and that was what she needed to do at the time. The older one became very much my little shadow.
>
> (P8 para 2)

P2 as a mother of two children had very good reasons for not wanting her diagnosis to be serious. Thus this was another reason she chose to minimise or deflect the seriousness of her condition to herself. She did talk of cancer to the children which she did find very difficult, more so than discussing with her husband. She also recognised and understood the denial from her youngest daughter, perhaps recognising her own period of denial.

Shedding the 'Old Self'

P2 had worked for 23 years as a teacher, and this dance with cancer had made her re-look at her life, re-evaluate what was important. She prioritised 2 areas during interview- work and relationships, which she saw as having impact on her life following her illness experience. P2 worked full time as a primary school teacher and following diagnosis, found work very stressful:

> *P2* I think what happened at work, I think there was a lot going on, bit I actually took time off. I was teaching and I thought 'I'm not functioning properly here' and I knew I was going to crack up. And so my doctor said 'stop now'.
>
> *Int* How are you feeling now?
>
> *P2* I wasn't happy at work and I felt like I was running all the time to keep up and also I wasn't who I used to be and what I could do. You know when you sort of know things that people say about you or looking at you and you think 'that's not who I used to be and how I used to do things' and so I would like to change that. ....
>
> *Int* Perhaps something like this happening suddenly shakes things up?
>
> *P2* Yes because when I went to college, I worked very hard at college and did teacher training. I had lectures every day, we worked very hard. I went into teaching and everything was for that, my career. When other people who were friends who went off to college or did not go to college, they were having parties and even when they first started working, they weren't working in a job that was so demanding and responsible. They were out having a great time and I missed that. I think that was my choice and the same with having a family. But it is nice now. Actually there is a bit with other women, 'are you not working?' and I

> think, 'actually I worked for 23 years, I have been teaching and it is OK to have some time off'.
>
> *Int* Absolutely, yes.
>
> *P2* Coming home with a case full of work to do at home. I would be leaving at 8am and coming home at 6pm, and get the tea and stat work again at 8 or 9 through till 11 or 12.
>
> *Int* You have given a terrific amount to it and so now you are moving on?
>
> *P2* Yes and I don't feel guilty. I sometimes think I should but I have done that. I may go back to it in some shape or form.
>
> (p 11 paras 57-62)

In these conversations P2 has been doing a lot or reflection on her life. Her immediate worries were that she was not coping with work, and she relates at how the diagnosis had put her in a high state of anxiety, 'I thought I was cracking up'. This emotional state is justified when she states her GP tells her to 'stop now'. Here he is giving her permission; he is validating her concerns and authorising her to give up work immediately. She also talks about the 'old self' she used to be, her internalised comparison of the 'real self' compared to this new 'ill self' and how she used to cope before all this happened. She compares her efficiency and relationship with other staff, feeling concerned her colleague's think she is not coming up to their expectations. But the justification of this she receives from her GP, he recognises things are going wrong, the pressure is becoming too much for her therefore she must give up. She also recognised that this was a state she disliked, a situation which she sees as a temporary state only and says 'I would like to change that'. So whilst accepting things are in some ways out of control, she still verbalises her ability/desire to change things and thus retain some elements of control.

But the feelings of guilt of leaving work are still evident as she describes the years of training she did, emphasising how hard she worked, missing out on parties etc. Perhaps reliving her life, she thinks she didn't have enough fun, and now this has happened to her, she realises there is a lot more to life than work. She emphasises this was here choice to have a career and have a family, but she is also saying, having made those decisions I can now make this decision to give up. She justifies it by mentioning her 23 years of service; she invested in teacher training but in return she argues, has given 23 years of her life to teaching, all the out of work curriculum etc., and thus puts her decisions in perspective. She states she doesn't feel guilty, with a proviso 'perhaps I should' indicating there still are doubts whether her decisions are permanent and whether she has given up her career for good.

She also sees herself as an efficient woman and admits she recognises, on more than one occasion, she is not coping with all her roles, wife, daughter, mother and teacher. She considers she is letting her mum, children and husband down and thus something has to go, and she decides it has to be her job. She's not been happy for a while and sees this 'opportunity' to leave. The GP's advice to 'stop now' is the lead she has been looking for, although perhaps not the reason she would have chosen for leaving. She also discusses strain between her and her husband during diagnosis and following her surgery. She initially describes herself as a positive and strong person but follows it up with "I wish sometimes I wasn't! Somebody look after me":

> *Int* Did he discuss how he felt with you?
>
> *P2* Not really no. Not afterwards, no, I would say we were a bit distant. I think that was partly both our faults, partly I feel I would do things my way and carry on with what I was trying to do, and get myself better and get back to normality. I think he really switched off a bit to cope with it and to cope with other things at the time. ....and I think it was sort of 'you're OK, it's all been cut out and you're fine now'.
>
> *Int* Back to normal.
>
> *P2* Yes I had one doctor, not my usual doctor he was a locum and I went to see him for a routine follow up and I wasn't feeling so good at the time. I had become depressed I think from the operation and the hysterectomy and he just asked me about what had gone on and I said I am really lucky, and he actually looked at me and said 'sometimes that is not how you feel is it,

> you can be scared and sad.' And it just made me cry and it was like 'don't say that'. He was quite a young male doctor and I thought that was really insightful.
>
> (p 6-7 paras 31-35)

Here P2 compares how her husband didn't understand her but the GP – a young male- did. This refers back to earlier comment about wanting to be looked after, and how her husband expected her to revert back to being the strong coping woman she'd always been. But she saw herself as now being different, this experience had changed her, she had spent periods reflecting on her past life and the new emerging woman she was becoming. Her husband was also ill during that summer and she found coping with that very difficult, and she was also depressed:

> *P2* He (husband) once said to me, I got upset about something, 'I think you're depressed 'I said 'no I don't think I am'.
>
> *Int* But you were?
>
> *P2* Yes
>
> *Int* so he had picked it up?
>
> *P2* Yes I probably wasn't letting him into that I was just trying to get through it.
>
> (p15 para 79-80)

P2 then went on to say that she went to the GP but was slightly evasive about admitting being on any medication for depression. She admitted she had sleeping tablets for a week or so but couldn't remember if she had any anti-depressants, and suggests this is a 'normal' process she has to get through on her own without medication. She implies taking medication would somehow render her a failure; she has to cope with this on her own. She stated she wanted to be looked after but contradicts that by admitting she wouldn't 'let her husband in'. Perhaps feelings of failure were too much for her to admit even to her husband. As a self confessed strong woman, the expectations were that she should cope, and letting him in would be admitting she was 'failing'. There is also the suggestion that this is something she has to go through, a rite of passage somehow in order to return to normality. Her refusal to acknowledge or accept medication for her depression suggests she's still blaming herself for not recognising her symptoms earlier and thus feels she has to carry the burden and take the consequences by herself. Accepting medication would be seen as taking an easy option, 'going down that route', and one she did not want to do:

> Int Did you have any medication for that or anything else?
>
> P2 No... I had some sleeping tablets. As I say I had a very good doctor. I'm trying to remember whether I did or not, I don't think I did, or maybe for a week or something. I didn't really want to go down that route and I did sort of feel this is something I have got to go through.
>
> (p8 para 40)

With hindsight she admits she did feel lonely, but does discuss the accumulated factors which led to the situation being as it was. Her diagnosis and treatment, his illness, her depression, his problems at work and neither communicating with each other. She also admits she didn't discuss things with her husband, but expected him to realise how she was feeling. She also recognised he was having problems at work, but felt rather pushed out and angry when he only took a couple of days off with her, having to go back to the office.:

> *Int* Did you feel angry at the time or was it what you expected?
>
> *P2* I probably felt let down; I felt lonely, I did feel lonely. I knew there was a lot of stuff going on for him at work and he struggled with that and I didn't want to add to that.
>
> (p14 par 75)

This was a difficult point, and whilst P2 recognised the demands his office made on him and the ongoing problems, she still resented coming second. Her admission of not letting him in (on her feelings) is a way she exerts control by cutting him out, dealing with it herself. She also compares the attention he has during his illness n and is resentful of the support he gets from his friends. This she explains by the taboo she sees when discussing (or not discussing) the hysterectomy. P2 did attribute a lot of the way she was feeling to having the hysterectomy, rather than focussing on the cancer. This deflection surrounding symptoms are effected by talking about the hysterectomy:

> P2 From hearing and talking to other people I think probably it (the depression) was quite normal. It did say in some of the books about the hysterectomy that there is that loss of being a woman and having trouble and also stuff about your hormones. It did talk about the fact you could become depressed and have low feelings, and so initially I thought that is what it is, this is what it is and things like that. Can I come out? Can I come out?
> (p15 para 85)

> P2 A lot of people say about feeling a loss, I didn't I don't think initially, I think a bit later on perhaps I did. I never felt less of a woman. People kept saying to me 'you are going to feel marvellous, you are going to feel like a new woman'. And then these things didn't happen and I think that was making me feel worse. I was supposed to be feeling like a new woman, I was supposed to have all this energy and I didn't.
> (p7 para 37)

She reports she has read all about the hysterectomy and discussed with lots of people, omitting the reason why she had the hysterectomy i.e. the ovarian cancer. She finds simple reasons for why she is feeling depressed etc., asking can she come out, i.e. as she recovers from surgery will the depression lift. She is verbally quite dismissive of the cancer, 'a bit of me had cancer' and 'just the realisation that I could have ovarian cancer and then it had gone', just like the removal of a simple cyst. She refuses to allow herself to dwell on the cancer, albeit already admitting her fears with her friend with breast cancer, and follows her established path of avoidance. Focussing on the hysterectomy is a far safer option, and she has read all about this which gives credence and explanations to her transient self. These constructions she finds far safer and certainly more reassuring. They are also predictable and to an extent, controllable. Talks of recurrence and unpredictable cancers are frightening and ones P2 avoids in quite an elaborate cognitive framework. She cites a hysterectomy as being a 'unique operation':

> *P2* Because hysterectomy is a very unique operation, but I think again because it is a woman's operation, it's not talked about in company you know. You know it's been quite interesting because my husband had to opened up, he had a laparotomy. And it's been quite interesting the reaction to him compared to the reaction to me, almost like it's OK to discuss his operation but don't talk about women's ops, that's taboo, something to be hidden.
> *Int* Who from the family?
> *P2* Not so much the family, other people, family and things, particularly males.
> *In*t Why do you think that was?
> *P2* I think they can cope with it being a man but not a woman which is a bit......
> (p12 para 63)

Participant 2 finds it safer to focus on the hysterectomy, the literature tells her that is why she's feeling as she does. The expectations of this 'new woman' fail to materialise and P2 suggests that these are the 'myths' about post hysterectomy, she does not feel a 'wonderful new superwoman'. Nevertheless, she does accept that she had made huge life changes and these are for the better. The woman is selecting to minimise the cancer experience, which was life threatening and could have been terminal. Instead, she focuses on the myths of post-hysterectomy feelings, citing this as being the central issue.

P2 appears to have weathered her very frightening storm by slowly eradicating the cancer from her life and focussing on the hysterectomy. But it certainly stood to clarify many issues in her life and helped her prioritise what she saw were important and perhaps neglected 'other self's' which she had been unable to address. The multiple roles P2 had been juggling for several years had been manageable until this crisis occurred. Threatened with a potentially terminal illness, she suddenly had the opportunity to take stock of her life and analyse her 'self'. Constructing her future self involved de-constructing her previous roles and lifestyle, and one she professed would certainly be more satisfactory and enjoyable:

> *P2* I feel more like I am getting back to how I would want to be and how I was, and not working has been a huge part of that. Taking time, giving to my family and to me and to my mum.
> *Int* well it's like closing the door perhaps on what's happened and starting a new way of approaching life.
> *P2* ......Yes I think I am. I do lovely things, lunches, ladies who lunch! I love it, it's great.
> (p11 para 56-58)

5.2.3. Analysis participant 3

The sexual self

P3 presented with several complex issues which were unravelled during interview. Her medical history was also one of the more complicated cases. With a family history of maternal ovarian cancer, her own initial diagnosis of uterine cancer was compounded to include a separate ovarian cancer discovered during surgery. At 46 yrs she was one of the younger women to be interviewed and having no children, also experienced through the hysterectomy, the complete cessation of her childbearing options:

> Int Well can you tell me the first signs and symptoms
> P3 Well they were a bit sort of vague and my mum had ovarian cancer some years ago....
> Int So you were aware of some of the signs?
> P3 No not really. I had cancer of the uterus and they only discovered the ovarian at surgery,
> (Page 1, Para 1)

She then goes onto to discuss the hysterectomy:

> P3 it was the bleeding that was the problem, and when I realised I might need a hysterectomy that was a problem.
> Int Why was that?
> P3 Well I've never had any children and having a hysterectomy....
> Int You were still hoping there may be a chance?
> P3 I know I'm 46 but here still might have been a chance, we weren't using anything. So I did look up what options there might be, perhaps they could just do a scrape or something, just remove the cells, I don't know.
> Int And what were you told when you discussed this?
> P3 Well they just said I needed a hysterectomy, everything had to come out.
> Int And how did you feel about that?
> P3 Well a bit fed up, I said I wanted to think about it before I made any decision and I still wanted to leave things for a while. And they didn't recommend it so obviously I just felt that's what you had to do. I just felt that obviously I was in the hands of the doctors and this is what has to be done.
> (p2 Para 8)

Here several issues are introduced; P3 experiences worrying symptoms and is given a diagnosis of uterine cancer. At 46 this is a serious worry, but for her this also signifies not only a grim life threatening disease, but also the compulsory ending of her childbearing options. Having tried unsuccessfully to conceive children, she was still hoping there was a possibility she may get pregnant and whilst she still had her uterus this could still be an option. A hysterectomy to her, was not a necessary surgery to remove a diseased organ, it was the permanent closing of her fertility option. P3 also denied experiencing many symptoms herself, but then did admit looking up signs and symptoms of ovarian and uterine cancer up on the web prior to visiting her

GP. Thus she must have been concerned that something was wrong, enough to take time to search the web for signs of both these cancers:

> *Int* So had you been looking it up on the web, the information?
>
> *P3* I could appreciate how difficult it was to diagnose it because when I looked up at first, and I didn't have that, and I looked at cancer of the uterus and I thought, yes I have got all those symptoms.
>
> *Int* So most of the symptoms you were having were just spotting with periods in between?
>
> *P3* Yes
>
> *Int* No other symptoms at all?
>
> *P3* Not that I was aware of. Again maybe I was going to the toilet more often, but then again I put that down to age.....No there was just normal bloating as far as I was concerned. Possibly now and again I think of shooting pains, but not regularly enough for me to think' oh that is something', it was the spotting and more than spotting really. Sometimes spotting, sometimes like a mini period every two weeks or so that made me query it further.
>
> *Int* It was the actual bleeding that made you go to the doctor?
>
> *P3* Yes. From the ovarian point there was nothing that would have highlighted it, although if I think about where the pain had been, it would have been on the side where the actual ovary was.
>
> *Int* Yes, and you didn't notice anything there?
>
> *P3* Just when I did get any sort of pain it was on that side.
>
> (p2/3 paras 14-18, 1-3)

Thus P3 verbally denied any symptoms initially during the conversation but then went on to reveal quite a list - abnormal bleeding, 'usual' bloating, frequency of micturition and shooting pains. Thus was she attempting to ignore or normalise her symptoms, 'usual bloating' and even the bleeding which she termed 'mini periods', i.e. normal but small periods. It was this increasing bleeding which made her 'query it further'. This is interesting as P3's mother also had ovarian cancer some years previously:

> *Int* Right yes, with your mum's history, could you sort of link this in then?
>
> *P3* I could, and the fact I suppose from that point of view I did then sort of think I might need chemotherapy so I was relieved when I didn't and just had the radiotherapy.
>
> (p4 para 20)

Thus this denial of several symptoms is interesting with P3's family history especially as she had earlier expressed dissatisfaction with her GP for not sending her for screening some years prior to becoming symptomatic. So even years before, she was aware and perhaps worried that she may be 'incubating' the disease, so much so that she requests screening from her GP which is denied. But when she does develop those very suspicious symptoms, she ignores or explains them away for several months. She does however quite explicitly mention that she was mentally prepared or resigned to having chemotherapy similar to her mother, but then is relieved when she is assigned radiotherapy. Thus there is the underlying hint that she was linking these symptoms to her mother's experience, even to the point of expecting she would also have to undergo chemotherapy. But perhaps a far more influential reason for her suppression of symptoms can be explained by her discussion regarding her partners loathing of illness:

> Int So how about your partner, what was his reaction to what was going on?
>
> P3 I think he found it difficult because he is not a person who likes ill health anyway. His father had been ill for most of his life with mental health problems and so he went the opposite way and wouldn't take a pill for a headache or anything. He had an abscess and wouldn't take a pill. He never had a lot of sympathy for people who were ill.
>
> (p8 para 34)

Thus her succumbing to illness was seen as a negative concept in their relationship, and despite her family history, she perhaps chose to prioritise the relationship over her health threat, i.e. ignore symptoms, deny illness and keep the partner. She cites the relationship became problematical around sexuality issues with the partner actually choosing to finish the relationship and leave following her radiotherapy treatment:

> P3 He was very good with me when he was here, but I think certainly from the physical side of things; because they weren't back to normal, I think that put a strain on things really. He didn't like the fact that he would have to use KY jelly because he thought it should be natural and not so mechanical. And so all those things didn't help and we split up.
>
> Int Do you think he supported you at all through it?
>
> P3 He thinks he did!
>
> Int Did he understand what was going on?
>
> P3 I gave him everything to read because all of this is in the literature isn't it; that you might be feeling low, you might be feeling unattractive, low esteem etc., that you might need someone to talk to? I did try to talk to him however is was difficult with the relationship in the first place having to wait until weekends. When I was having the treatment he took the day off to come with me for the operation but then he went back to work. He took an extra two days off when I came out. But then I went to my mums for the rest of it. So the day I cam out he went to watch the rugby with the lads, but he was only gone for an hour as he said. So in a way he was, but not what I would have liked. I think he did read the literature, he did understand everything, but I think it was a case of him and the way he was.
>
> Int Did he discuss anything with you?
>
> P3 No
>
> Int No, he just read it and didn't say anything?
>
> P3 Yes
>
> Int. Did you predict the way he was going to behave?

> P3 Yes and no. Before I had the operation I did talk to him about it. Well this is almost like a self protection, a self defence. I did say 'You don't have to stick around' he said 'Of course I want to be there blah blah'. So in that respect yes. I did say to him 'well look', and he said 'no', and he was in his way, he was very supportive. But I suppose I needed a little bit more of that. The first week I started the radiotherapy he had a skiing trip with the navy, so there were lots of things through that when he wasn't there which made me crave a little more support and a bit more attention etc and that made me feel very down. So I was looking forward to him coming home but then miserable because of all these different things really. So we did end up splitting up.
> (p8 para 34-36, p9 para 1-3)

P3 recognised early on her partner was not a person who dealt well with illness, and thus she saw to keep him she needed to keep well. This could explain her denial or refusal to recognise early symptoms, despite the family history and her own knowledge of ovarian cancer. It was also a direct contradiction of her previous requests to the GP for routine screening.
When this 'normal healthy self' was not an option, she recognised he may not want to be around and bravely offered him the 'get out' clause. His stating he wanted to be with her was accepted with relief by her, but the interpreted definition of this 'supportive reality' was from very different perspectives by both parties. He sees his input as minimal, transient and is happy for her to stay at her mothers for total care.

P3 saw his contribution as lacking any real commitment with limited time taken off work, going to the rugby with his mates rather than be with her, only there at weekends and allowing her mum to look after her when she saw that should have been his role. She exhibits a verbally sad and lonely existence throughout the whole treatment process, 'sexual problems', 'strain', 'needed a little bit more of that', (support) 'Made me crave a little bit more support', 'more attention', 'made me feel very down', 'miserable'. None of this, she saw as being addressed by her partner. All of this was underpinned by the literature from the hospital she had read and indeed given to her partner to read, and more importantly, given to him with the emphasis for him to *understand, accept, act and prevent* her from feeling the negativity she dreaded:

> P3 Because all of this is in the literature isn't it, that you might be feeling low, you might be feeling unattractive, low esteem etc, that you might need someone to talk to.
> (p9 para 35 line 1)

Thus P3 had given the partner all the literature, reported he understood it but still he failed to fulfil her needs. Her reported feelings of anxiety, being unattractive, low esteem etc., were underpinned by his failure to be her 'expected reality' that of partner, supporter and lover. To her, his emotional and physical support was only superficial and inadequately met her needs and desires. The issue of him complaining about using 'KY jelly' during intercourse was seen by her as yet another failure for her to fulfil his expectations, i.e. getting ill, undergoing surgery and radiotherapy. The consequences of which resulted in an unacceptable 'mechanical' sexual relationship. This negating of the sexual self of P3 was a very important issue and one she felt was the main reason for the relationship breakdown. She presented herself visually as a glamorous woman, prioritising make-up, clothes, and hair as very important issues. Early on in the interview she stated shock following the same diagnosis as her mother, but relief at being designated for radiotherapy, rather than the chemotherapy her mother had received:

> 'I did sort of think I might need chemotherapy so I was quite relieved when I didn't and just had the radiotherapy'.
> (p4 para 20)

P3 had probably seen her mother lose all her hair and that would have been yet another huge trauma for her (she had long blonde hair) and thus she viewed the radiotherapy (as yet an unknown entity to her) as a 'much better' option. In reality this did not prove to be the case as P3 experienced some pelvic adhesions and vaginal 'muscle spasms' following radiotherapy, necessitating her to use vaginal dilators daily, a problem which is still ongoing. Interestingly, P3 never chose to discuss the effectiveness of either treatment in treating the cancer or in recurrence at this stage of the interview. The relationship breakdown dominated conversation which she led, and this break-up she saw as being completely her fault, i.e. because of the illness. If she hadn't been ill she reflected her partner would have stayed with her and yet she still saw the illness as a shared problem:

> Int ...So what did he explain was the reason for that
> P3 That we weren't happy enough. He didn't obviously say, just that we weren't happy. So I almost wonder if he was waiting until everything was a bit more settled. But then he started seeing someone else within days.
> Int Why do you think that was, because maybe it was a way of coping?
> P3 I think obviously somebody, in my mind I suppose I was starting to feel unattractive and that just confirmed it, that I was no longer attractive to him and there was somebody else there and he took that opportunity.
> Int Is he still with that person?
> P3 I think so. I am not in contact with him which is another thing really. Because you would think that, I mean we hadn't fallen out; we didn't fall out having a blazing row. When I saw him with someone a few days later, yes I said some nasty things but that was it. We didn't fall out, but no he hasn't contacted me and said 'How are you going'? Again I don't know if he realises that I still do have to, he must realise because he's an intelligent man, that you do get checked, but he has never contacted me to say 'How are you'?
> (P10 para 37)

Sadness, loneliness, low esteem and disappointment are all evident in this conversation. The partner leaving was always an option in her mind; P3 knew how he felt about illness and thus recognised she was dealing with a difficult, albeit impossible problem as soon as she had her diagnosis. She blamed herself constantly- no longer attractive, problems with sex, and thus she, and the illness, drove him to another woman. P3 makes excuses for him 'he took the opportunity', which confirmed to her that her 'worthless self' was in fact quite justified.

She describes the row in the street between herself and the new couple, and admits saying 'nasty things' but these she saw as being justified, she was the deserted woman who had been sick (thus failing in her part of the relationship). Despite this confrontation she then expresses surprise that he hadn't been in touch to enquire how she was getting on after her check-ups. This would suggest that perhaps she is viewing this separation as temporary and still hoping as she moves into the 'cured' sphere, he would return. Her priorities were expressed primarily in the preservation of sexual self and the effect it would have on her identity in the relationship. The concept of her having had two separate cancers was not mentioned during this phase; the 'illness' was viewed as a causal factor in the breakdown of the relationship. The threat of recurrence is deflected by feelings of abandonment.

The Powerless Self

P3 felt she had no control over several issues during her diagnosis and treatment. The initial switch of control from self control to medical control occurred early on:

> P3 Well they said I just needed a hysterectomy, everything had to come out.
>
> Int And how did you feel about that?
>
> P3 Well a bit fed up. I said I wanted to think about it before I made any decision and I still wanted to leave things for a while. And they didn't recommend it (waiting) so obviously I was in the hands of the doctors and this is what has to be done. The only other thing that I queried was again after reading various things

> as you do, is whether everything has to be taken away including he cervix, and do I queried that and the lady I saw here at pre op said to ask the gynaecologist about that, because it is not essential in all cases to take everything away. But again a different guy did the operation.
> (P1 para 6)

P3 was facing a hysterectomy which as a childless woman and sexually active woman was a huge decision. She knows that if she agrees to this decision any possibility regarding her getting pregnant will be finished completely, and there will be no going back, no changing her mind. And she also is very aware that this decision is not a voluntary one, it is being forced on her because of the cancer. She prevaricates, asks for more time, discusses the issue of retaining the cervix, and reads as much as she can about it. However, the medical staff are also under political and surgical pressures, they have targets to meet, cancer waiting times to conform to and histological results indicating surgery. The issue of retaining the cervix centres around sexual enjoyment and P3 discusses this with one surgeon but is told a complete hysterectomy is indicated. She feels powerless to control any of the decisions which she is forced into making, life changing decisions that cannot be reversed:

> P3 Yes I felt the decision wasn't really mine to take because of all the time rush and the diagnosis. Although I did query that option (sub total hysterectomy), "is it necessary"?
> (P2 para 13)

P3 also felt powerless regarding the break-up of her relationship. She talks of her partner making the decision to end the relationship:

> Int So what did he explain was the reason for that?
> P3 That we weren't happy enough. He didn't obviously say... just that we weren't happy.
> (P10 para 37)

And blames herself for this, her loss of attractiveness, low self esteem etc., all things she sees as being unable to alter. She sees the illness as being the reason for taking all this away; she's read what happens after a hysterectomy in books, she's seen it on the web, and now it has happened to her. She sees the inability to get back to 'normal' as being the huge barrier. If their sex life had been normal he may not have left:

> P3...so we had had sex but we had to be careful we had to use the KY jelly and it was slightly painful for me. But I was keen to sort of get back to normal, and unfortunately we had not got back to normal when we split up.
> (P11 para 44 line 2)

She also comments:

> P3 If it was a completely different situation I would probably feel back to normal completely. If I had had a husband for 10 years or something, he would hopefully have been a lot more sympathetic and I would just be feeling normal.
> (P12 para 47 line 4)

In recognising the role of the break up of the relationship in the stilting of her return to normalcy, she also considers how things may have been different with another partner. Perhaps she looks back to her marriage and the other long term relationship and wonders if those partners would have looked after her better. But when asked, she still sees being in a relationship as a positive thing:

> Int So do you feel having this partner at the time was a positive or negative thing?
> P3 Positive because they were there, they were there. It might have been even worse if I had been single at the time because I had a hysterectomy. So it was positive in that respect.
> (P12 para 47)

5.2.4. Analysis participant 4

The anxious self

P4 was a 66 year old articulate woman living with her husband and 2 sons living away. She was an ex nurse, thus clinically astute to her diagnosis and in these terms, very realistic about prognosis. A nursing background however does not protect from anxiety and fear, neither does it preclude degrees of denial and anger:

> Int Could we start right back, thinking about what your early symptoms were?
> P4 ...I was playing badminton one day and I thought I don't feel so good, I feel tired. And when I sat down I felt uncomfortable. So I thought well I did have an unstable bladder and continuous urine infections......Anyway I thought there is something not quite right, and then a couple of nights later I went into retention and I laid on the bed and thought there must be something pressing.
> (P1 para 1-3)

Here P4 is listening to her signs and symptoms; she is aware things are not right and is trying to attribute causes. She has a long standing problem with her bladder and reports she had a hysterectomy many years ago, leaving her ovaries intact. But at this early stage, her bladder appears to be the 'culprit' and she is not thinking anything suspicious, just that something is not right and she must seek help urgently. She saw her GP who arranged an appointment with the consultant, but arranged for this to be following P4's imminent holiday:

> P4 On the Monday I went back and said 'please help me this is not right'. So she said she would arrange for a scan. I didn't hear for the next couple of days so I rang the scan people myself and I said 'I have been referred as urgent', and they hadn't done it but they did it for Friday. On the Thursday I was in agony, I didn't know what to do with myself so they took me down to A and E and they just seemed to think it was bladder and sent me home. I went for the scan on the Friday and the doctor said 'ring your GP,' and the nurse said 'ring your GP' and they will give you the results'. So I did on the Friday I was in hospital.
> (P1 Para 3)

This escalation in the worsening of P4's condition must have been a frightening situation, and she demonstrates how urgently she reacted. She returned to her GP on the Monday explicitly demanding help and was referred for urgent scan. But when the appointment didn't materialise quickly enough, she was again proactive, using her own initiative and ringing up the scanning department. Increasing pain forced her to attend hospital where she was sent home with no diagnosis. By now, P4 knew things were seriously wrong and took control; she had visited her GP and obtained consultant referral. She then returned and convinced her GP to order an urgent scan, and followed this up herself. Then she had attended hospital for help with increasing pain, rather than contacting her GP.

This was a woman in severe pain, worried what was happening, anxious and trying to remain in control. Following the scan, her urgency in pushing to get her investigations done without delay were realised when she was advised (2) by medical staff to ring her GP for results, and was admitted to hospital as an emergency that same day. She states over the weekend in hospital she 'was calm because she was on drugs only to stop the pain', suggesting she remained anxious as to the cause which wasn't yet determined. But perhaps, also 'calm' because she was now admitted with investigations pending; the responsibility had now been taken away from her and put in the hands of 'experts'. She didn't have to chase people up and try to convince them something was really wrong, her initial symptoms were now backed up by the evidence of the scan. Her pain was being addressed and she could finally feel safe.

When the GP called in to see her in hospital on the Monday and expressed surprise she hadn't been to theatre over the weekend, P4 stated she thought the GP was being 'impatient', suggesting that P4 herself had defused some of the urgency from her situation. Now she was pain free and being cared for by the 'experts' in a hospital bed, she didn't think that as a priority she should have gone straight to theatre, she was satisfied to wait and go at the pace of the hospital team. But nevertheless, there was urgency and following her MRI scan on Monday she was taken to theatre on Tuesday.

This far in interview, P4 has related factual and full information as the sequence of events leading up to her admission. She has discussed physical symptoms and how she dealt with them, but not touched on her real psychological fears and worries, how she really felt at each stage of this rapid and scary chain of events. It was only following surgery when the consultant came to see her the same day, that she mentions concerns:

> P4 Mr X took me down on Tuesday and he came back and he said it was a mess. He said it was a mess; it was just, he said 'I don't know. I took out the ovaries', must have been together and the tubes must have been. I don't think they took the tubes out because everything was stuck together. They did a repair to try and sort out my bladder but I don't know if they left anything, you know the tumour behind.
> (p2/3 para 3)

P4 accurate accounts of her previous journey now start to fragment and become less knowledgeable and sure about things. She is even uncertain of what actually was done at the operation, whether the tubes were removed or left, and the crucial issue of whether the entire tumour was removed:

> Int Why did you think that?
> P4 Anyway so that was that. He said the washes were clear, negative. M (oncology nurse) came up to see me and then I think I saw oncology on her badge and thought 'oncology, oh gosh' and bells started ringing and I thought, 'well just go easy'.
> Int Had you not thought about that at all?
> P4 Well when my own doctor examined me when I went back and asked for help she did say to me ' I don't know if I can feel a mass'. So back here I did think about it and then thought 'no it'll be something else, the bladder or hernia or something'. Anyway I had to wait then and I had no help at all. I came home and felt so alone. I went back after a couple of days and you half know,

> but when they tell you it's an absolute shock, I was absolutely gobsmacked.
> (P2 para 4-5)

The revelation of the GP's initial thoughts regarding the query of 'a mass,' throws some light on P4's assertiveness prior to admission. As a nurse, she would have understood the clinical implications of 'a mass' and her worries were reflected in her subsequent behaviour of obtaining the scan. Her denial is evident as she reports her response to seeing 'oncology' on the nurse's badge. Then she describes her reaction to the GP's suspicion of a mass, allowing a fleeting thought that it may be, then dismissing and replacing with a much safer reason that is anything but a malignancy. The consultant had told her his operation findings 'were a mess', she had seen the oncology nurse, her GP had said she thought it was a mass, yet P4 still professed denial, stating it was an "absolute shock", she was "absolutely gobsmacked" with the diagnosis. Yet she does hint at thinking about worst scene scenarios when she says she went home from hospital. The sadness expressed is that of a worried woman unsure of what is to come. She feels alone because she knows that no one can change the diagnosis if it is cancer. She has to face challenges on her own and experience the treatment and outcome. The immediate response to the oncology nurse of "I can't be on the way out" suggests that she has been seriously thinking about cancer and the option that it will be serious, even terminal. She knows the pain she has been in, the problems at surgery and with her clinical background; she would have been linking all things together. Thus her declared shock and disbelief were probably not surprise at diagnosis, but at the confirmation of her worst fears.

The Positive self

P4 has received this devastating news, or perhaps confirmation of the threat that has been at the back of her mind. She considers all options and appears cognitively comfortable or more reassured by adapting a more positive stance:

> P4 'I feel so well M, I can't be on the way out'. She said 'you are well it's gone'. And then they said I had to go to C and have a discussion with the oncologist. He did explain that the pain and everything else was the tumour spreading about in the pelvis and adhering to my bladder. But he said I was lucky it hadn't attached to the bowel as it was an aggressive cancer. I thought if the pain had not been so severe, I might have sat on it and it would have been worse.
> (P2 para 5)

P4 has been given devastating news and she searches for any information that is positive. She repeats the oncology nurse's comment that she is fine and the cancer has gone. Regardless of the fact that she was informed of the aggressiveness of the cancer, which had spread to the pelvis, she manages to obtain consolation from the oncologist comment of no bowel involvement. She attempts to focus on all the positive aspects, no matter how small. Even the pain experienced is viewed as a positive thing, if it had not been so severe she may not have pushed issues with her doctor and the cancer would have advanced to an even greater stage.

She discusses the options she is given by the oncologist, she and her husband take some control back by making an informed decision to have the chemotherapy. She describes the difficult time she has with the chemotherapy but the positive feedback she receives regarding her scan. Although she is realistic in her comments regarding her scan, "but I must not put too much emphasis on the scan, it's the microscopic cells that might have got round" she goes on to state, "he said [oncologist], hopefully you have had your chemotherapy and that will have sorted everything out". She discusses

> Int How do you feel, now looking back over the whole process?
> P4 Looking back I don't think I could have stomached anything else. ....I just felt, I never for once thought I am going to die. I felt if I get this done, get this sorted I thought of B, I had to keep asking him. ...From my operation until I had my first chemo I was OK but I needed a lot of reassurance. I would sit by him, he was alright he didn't mind, I wasn't on at him all the time, as long as I knew he was here.
> Int So you felt in the beginning you needed reassurance?
> P4 Oh Yes.
> Int What were your main ideas behind that, your main fears?
> P4 Well reassurance of what M told me, reassurance of what Mr X told me, reassurance what chemo told me. Because when you are told news like that, you don't think, whereas B was with me and took in everything, and he was a manager and all I needed was for him to tell me what they said again. And I thought 'I'm alright, I can deal with it and cope with what comes, and that they are pleased with how I was coping with it and that's the only reassurance you need. They couldn't tell me I wasn't going to die, they couldn't say you are going to be fine and there will be no more trouble from the original tumour. We've just got to wait and see what happens.
> (P4 para 10-11)

By the end of the chemotherapy, P4 is emotionally weak. She is physically exhausted following the side effects she experienced and mentally strained with the diagnosis and prognosis. But following her initial admission of her mental and physical fatigue, she then immediately discusses her intention to be positive, to fight this disease. She denies she ever thought she was going to die, which rather contradicts her earlier comment to the oncology nurse 'I can't be on my way out'. She has thought this out, over the months of treatment she made a conscious decision to be positive and fight this disease. But she also recognises that she needs backup, and this is in the form of reassurance.

P4 gives insight into the strong relationship she and her husband have the importance of this is in helping her get through her ordeal:

> Int How would you describe your relationship with B throughout this whole thing?
> P4 Oh he's been marvellous, I couldn't have got through this without him. I know he worried about things, and he didn't know how things, well neither of us did, but he was always supportive, always there being positive and trying to help. When he was ill it was awful, I was down here and he was upstairs and I needed to be close to him to feel safe. Yes I can say our relationship has been a lot closer, better. I mean we've always been close but we went that extra mile with this.
> (p 12 para 47)

P4 mentions the concerns regarding the uncertain future that she and her husband recognise and understand, and verbalises how his positive attitude helps support her, makes her feel safe. What she also implies is that when he is not there she doesn't feel safe, she feels threatened, alone and vulnerable. When he had 'flu and was in bed, she missed his physical contact and verbal reassurances; she needed him to reinforce her thoughts of being positive and regaining her wellness. She mentions him being a manager, and in the context of her illness he was a leading source of managing her mental wellbeing, of supporting and looking after her. This was a shared journey for them both, with her husband taking on his role of partner/manager and dealing with his delegated responsibility.

She also needed this confirmation that all was going to be well from the oncology nurse, the surgeon and the oncologist. She recognised that no-one could tell her she wasn't going to die, but as long as they supported her, reassured her that she was doing well, everything was working out, and then she could cope. She understood the elements of uncertainty, the risks of recurrence, but she was prepared to take that in her stride as long as everyone supported her and were positive in their attitude towards her. It needed to be a reciprocal positivist relationship between the medical team, her and her husband.

P4 gives insight into the fraught mental state she was in, anxiety about recurrence, fear of death, physical suffering with the chemotherapy, all manifesting in states of apprehension and angst. But she stated she could just about cope and keep the lid on things as long as everyone around her gave her positive feedback and confirmed the treatment was working, her body was responding and they were winning. Her psychological fragility could not at this stage cope with failure. Her statements are a complex array of realism interjected with denial, pretence, hope and uncertainty. She reflects on this herself:

> P4 People have said to me 'how do you do it?' and I say 'don't ask me'. Once you get over the shock you get an inner strength to deal with it. I don't know where it comes from, but it certainly kept me going. I didn't cry. I am going to cry now! I feel quite proud; I don't suppose I should say that.
> (P6 para 19-20)

This was a strategy that worked for her; she surrounded herself with positive people, her husband, sons and friends, and kept herself focussed on the end point, that of surviving and getting well. When asked if she looked it up on the web she replied:

> P4 I knew it was a scary one. Obviously my husband looked it up on the web and we knew that it was a rare one and so we presumed it wasn't that silent. Well not with all that pain....The diagnosis was awful and we didn't really understand how bad it was. All the stuff on the web, I couldn't bear to look at it, I know it's stupid, but I didn't want to know. I know B looked it up, but he didn't say anything, I think he knew I didn't want to know any more, you know there's only so much...and he said 'there's just too much information and we were just coming to terms with it all, well some of it.
> Int Did he discuss it with you at all?
> P4 No, I thought about it, but I just well you know, I just didn't want to.
> Int Because?

> P4 Because I didn't know what to think myself, and I just thought 'I've got to be strong here for him, but we were both scared, scared stiff. He did know what sarcoma meant and now well, after the operation we did talk about sarcoma with Mr X, and it's funny, when it had gone, you know after the operation, it was easier to talk about it.
> (p9 para 31-33)

A diagnosis of sarcoma is indeed a bad one and accessing the web probably did give information which was certainly not positive. P4 stated she didn't want to know and her husband recognised this and kept the information to himself. They both recognised at this stage that P4 needed to be positive and accumulating more 'dangerous and negative' knowledge was serving no purpose. P4 was prepared to listen to the information given by the doctors but didn't want any more details, especially from the web which can be far too much information. There was a shared understanding of silence between husband and wife; he accumulated all of the knowledge and 'managed' this as well as he could; supporting his wife. She admits to fear and being overwhelmed, yet also is positive and looking to the future. She was powerless to alter the ultimate outcome of the disease, but could centre her strength on getting through the treatment. Believing it was going to work and that she would succeed, motivated her to continue. It also helped her construct a cognitive reality she could deal with whilst undergoing a difficult experience. Maintaining her reality entailed denial, avoidance, introspection and reliance on her husband; it protected her from the fear, shock and uncertainty that the disease created. This protection mechanism is noticeable from her discussion regarding television (TV):

> P4 But I'll tell you something funny that's happened since all this, I can't face those hospital programmes anymore on TV.
> Int What the documentaries or soaps?
> P4 Casualty or ER and oh what's the other one? Anyway I used to love them, watched them every week. But since this, can't bear to have them on, I switch them off right away.
> Int Why do you think that is?
> P4 Don't know, just can't face them, don't want to see anything horrible. I've just had enough of hospitals for a while, too many people with cancer. Perhaps it's just to near the bone, too much. It's funny, I can cope with breast cancer, yes that's alright if it's on the news or anything. But if it comes on to do with ovarian or something, it just has to go off.
> (p12 para 47-49)

This avoidance demonstrates the extent of her fear and uncertainty. P4 has set herself parameters of safety regarding 'dangerous knowledge' and previous experience of being a soap fan, has given her insight into the type of cases that may be on the programme. Interestingly, even several months after her diagnosis and at the completion of treatment, she still feels she can't cope with dealing with these areas of uncertainty. She worries that any case like hers with negative outcomes, may throw her over the edge and thus she continues with avoidance and denial. She watches nature programmes all the time now. She comments she can read papers or magazines:

> P4 Sometimes that's easier. There was some film stars mother a few months ago, she died of it. I thought 'all that money and they still couldn't save her' and that made me a bit shaky because I was still having chemotherapy and not as strong as I am now. I only saw the headlines, I didn't read it, and then after I thought

> perhaps I should have read it, hers might have been a really bad one or very advanced. But you never know do you?
> (p 13 para 50)

Papers are easier to skim and avoid uncomfortable issues, just as she did here. P4 saw the headlines, made her a 'bit shaky' and so she didn't assimilate any more of the information. But even though she only read the headlines, she did think about it and then wondered if she should have read all of the article looking for reassurance; she may have read this woman died because hers was much more advanced than P4's or a 'really bad one'. This would have explained *why* the woman died and P4 is going to survive. Looking for any reasons to establish differences and thus give explanations and clarify explicitly why this woman died, but only if it was dissimilar from her, may have made her feel better. But she wasn't brave enough to risk taking this chance, she may have learned too many similarities between herself and this woman, and she couldn't cope with that. She also states that when she read this she was still having chemotherapy and not as strong as she is now. But she has just admitted that even now, months later, she cannot watch TV hospital programmes, and this gives insight into just how psychologically fragile she was then. It also suggests she still has a long way to go before she feels safe again.

P4 demonstrates in certain ways she is very realistic and brave about her prognosis, and not just burying her head in the sand. To feel secure and manage daily life, she's found avoidance is better than constant confrontation. She talked about other patients she met whilst undergoing treatment:

> P4 There was one woman, she was nice but she was on her second round, you know it had come back, so she was having more treatment. But to be honest my chemotherapy was so strong, it was difficult to feel like talking to people.....But this woman was sensible and after, when I though about it, she was being sensible, brave I suppose. But they have told me and I am realistic, but they have said it will probably come back. As each year goes by, the risk of it returning reduces slightly. So if it hasn't come back in five years, that's a really good sign. But it was an aggressive type so we've got to be realistic.
> (P13 para 51)

Here she is reflecting on another woman with a recurrence, something she's been advised will probably happen to her. Even though this is a possibility, P4 states the point 'my chemotherapy was so strong' making the underlying emphasis on the potency of her drug and the hope hers will not come back. Then she talks of the woman being sensible and brave, sentiments she understands and tries to adhere to herself. Yet she explicitly states that she does understand the aggressive nature of the cancer and the risks of recurrence. Interestingly, by referencing this difficult truth, she abandons the 'I' and adopts 'we', utilising the support of her husband and classifying the disease as 'their' shared problem.

5.2.5. Analysis participant 5

The independent self

Patient 5 was a 51 year old woman who worked full time in a shoe shop in a local shopping outlet. She was married with 2 teenage daughters but led a rather emotionally estranged life with her husband. This inability to discuss any aspects of her disease experience with her husband led her to seek support from different sources, and here, with her friends she found a good support network which carried her through. When asked about her initial symptoms she reeled off a list of ongoing problems:

> P5 Backache, I've suffered for years with a bad back and so attributed it to that.
> Int And was that the first thing you can remember when things first started?
> P5 Yes but I also had abdominal cramps and a bit of incontinence when I laugh like. But I was on water tablets so I put it down to that. Plus I spend hours in the shop and don't stop for the toilet until I'm bursting, stupid really!
> Int Why were you taking water tablets?
> P5 Swelling ankles, and I think my blood pressure was up a bit so the GP told me to take it for a while. There were a lot of problems at work at the time, you know, staff leaving and a new manager and probably looking back, I was quite stressed and .... And the kids were very demanding, always wanting to be ferried here and there. My whole life was living to a busy timetable-everyone else's! I didn't have time to think about anything except where I had to be next and who I was picking up and was I going to be late? You know..
> (p1 para 1-3)

P5 describes her very busy life style, working long hours and childcare. This preoccupation with her job and family appear to have relegated her physical problems to an unimportant status. She does admit to visiting the doctor about her swollen ankles and blood pressure. Working in a shoe shop and being on her feet all day can be demanding and tiring for anyone, especially a middle-aged woman with teenage children. However, other problems she chose to ignore or normalise (i.e. incontinence due to water tablets and backache an ongoing problem. She then mentions some pain on intercourse experienced for some months, this was explained as being attributable to cauterisation for cervical erosion, some months previously:

> P5 They said I might get some pain and discharge. And it wasn't all the time, and it's one of those things you forget until the next time.
> (p1 para 5)

She recognised health concerns and had taken the time to cognitively debate and eventually arrive at a reasoned justification to explain the symptoms and rationalise why she did not require a GP appointment. She discusses the different symptoms as intermittent and whilst irritating, she could carry on with her life. Furthermore, after some time, one symptom would reduce or disappear and another symptom would replace it; this cycle continued for several months:

> P5 And it wasn't all the time, some weeks were fine, some were awful. I'd had cystitis several times, but I'd taken those packets from Tesco, you know for cystitis?
> Int And did they work?
> P5 Well for a bit they did. Then it just kept coming back no matter what I did.....
> Int And did you go to the docs?
> P5 What for the cystitis? No, no well I couldn't be bothered. Well it's just the thought of having to book an appointment and take time off work and well you know what it's like......

> Int So what made you go to the GP? What were the main issues that made you think there was a problem?
> P5 Well I was on HRT and having heavy bleeding and wasn't happy about that, I wanted it changing and I was just so tired. I did wonder if I was getting anaemic with all this bleeding all the time. But my GP, well he was pretty hopeless, I couldn't bear going to see him and kept putting it off. Anyway I felt so awful, so completely done- in really, that I decided I just had to go and see him.
> (p2/3 para 8-12, 1-2)

P5 was self-diagnosing and self-medicating, for example with chemist bought cystitis treatment. Even when these failed to work after several courses, she still did not seek medical help. Having positive or good health weeks with no problems helped restore her confidence that there was nothing seriously wrong, reinforcing her decision not to book a GP appointment. Bad weeks such as an episode of cystitis, were measured against good weeks, with no health issues. Even the heavy bleeding she blames on hormone therapy (HRT), i.e. a 'normal' side effect to the medication. It is the constant tiredness that she cannot deal with or explain. She does question if it may be due to anaemia because of heavy periods. As the tiredness is affecting her daily functioning, and she is unable to self-medicate to improve this, she decides to seek GP opinion. Another factor in reluctance to visit her GP is her lack of confidence in him. This labelling of the GP may have reflected her own internal analysis of reasoning. By stating that she feels, "he is hopeless", validates her reasoning and not visit her GP.

According to P5, the GP had dealt with her other problems, cervical erosion, swelling ankles. Thus P5 stating that she did not visit her GP "because he was useless", does not appear congruent with her recounting of her prior GP contact. There appears to be a corollary between her internal denial, that anything serious was wrong and her labelling her GP as "useless". It may have been that P5 really didn't *understand* what was happening and thus felt she couldn't go to the GP, with vague symptoms that she couldn't work out herself and was unable to determine the real reasons behind them i.e. tiredness, repeated urinary infections, vague aches. With the vaginal discharge she had 'real evidence' and the GP had diagnosed cervical erosion; her swollen ankles were again 'real evidence' and she had been prescribed diuretics; her menopausal symptoms were classic and easily diagnosed for which she had given HRT. But these new vague symptoms produced no 'real evidence' until the heavy bleeding. This again was a visible symptom which needed treatment and she now felt she had something concrete and thus perhaps allowed herself 'permission' to visit the GP. She recounts this visit to the GP:

> Int And did he (GP) explain to you, you know about what he suspected?
> P5 Oh no, nothing really, just that things didn't seem quite right and needed checking out. He said he didn't have the right equipment or anything and it needed sorting. He gave me some antibiotics for the cystitis, said I had an infection so at least that was sorted. Funnily enough I wasn't worried then, I just thought it might be the erosion thing or something like that. I think I was just feeling tired and not thinking straight.
> (p3 para 13)

P5 appears satisfied with the GP's decisions even though the diagnosis of 'things not being quite right' appear vague and indeterminate, she doesn't question him and appears pleased that her cystitis was 'at least' sorted by the antibiotics. Her reflections back to this meeting and her responses are explained by her feeling tired and not thinking straight. Again she's trying to understand why she didn't feel anxious at being referred to the hospital, and reasons it was because she was going along with her previous experiences and her previous referral to gynaecology with the cervical erosion, which was sorted with no problems. It may have been easier for her avoid questioning the GP; no questions meant no difficult answers and therefore no worries.

The worried self

Her clinic appointment was different, where she admits to being alerted something was really wrong and describes her examination and scan:

> Int What sort of scan?
> P5 That internal one and that's when I started thinking that something was really wrong. I heard the doctors whispering to the nurse and looking at the scan, and I started feeling uneasy, worried you know, what was going on? Then the consultant came in and examined me and looked at the scan. Then he started asking me the same questions, how long had I been like this and all about the bleeding and pain. But I said there hadn't been pain just a bit of aching and tiredness. Anyway he said there looked as though there was an ovarian tumour that needed to come out as soon as possible and they would make arrangements for me to go in.
> Int How did you feel then?

> P5 Absolutely gob smacked! Just completely shocked. Then the nurse came in with some leaflets and said we needed to chat. I needed to have more tests but I would be coming into hospital over the next week or so. And that was a worry, what about work? What about the girls? I just burst into tears thinking about them, what was I going to say to them? I hadn't realised, hadn't even thought cancer you know, I hadn't even thought of cancer.
>
> Int Had you actually been told it was cancer?
>
> P5 Well no, the doctor said tumour and I didn't ask but I knew. I really guessed it was serious, I could tell by their attitude you know. And anyway the nurse gave me a load of leaflets about cancer and the op and everything. Her badge said oncology and you know what, that only occurred to me later on when I was lying in bed thinking about it, the name oncology. But there's so much going on, and half of me wanted to listen and know everything, but the other half just wanted to get out of there, get home and try and think things out. It was the thought of telling everyone, you know about the cancer?
>
> (P3 para 14-16)

P5 was denying the seriousness of any symptoms until the scan. She had undergone previous gynaecological internal examinations and cauterisation, and this scan should have been less of an ordeal. However, she knew something was wrong when she heard the doctors whispering. Perhaps she *was* worried prior to the appointment, and was thus watching carefully for staff reaction; she corrected the consultant when he asked about her pain, denying it had been pain, just an ache. Her shock at the diagnosis may have been due therefore to confirmation or surprise. She confirmed that she was not informed at this time it was cancer, but had guessed, "I didn't ask, but I knew". Her confirmation came in the form of leaflets and the oncology badge on the nurse. However, she did not think about this until later on at home, alone in bed that night whilst ruminating on events and the meeting. Once diagnosed, she stated she just wanted to *"get out of there, get away from everyone"*. This fitted in with her denial, she did not want to 'know' this story, she could 'pretend' everything was normal in a cognitively reworked story, until diagnosis. She relates half of her wanted to listen and learn everything, perhaps hear some good news about 'cure' and treatment, but her state of fear also made her want to run away and not talk about it to anyone, deny it was happening. It was the thought of her daughters that reduced her to tears, the thought of having to tell them and other people about the cancer, she found a difficult issue. This may have been attributable to her accepting cancer as a terminal or death sentence. If she had gone to the doctor earlier would diagnosis have been so serious, was she blaming herself? Her reaction was guilt at failing her daughters and everyone else.

This woman took on all responsibility for the family and saw herself as being accountable to the daughters. Thus this succumbing to cancer she viewed as failure on her part, she was letting everyone down. Her priorities had always been to her daughters rather than to herself, even her health had been secondary to work and the family. Now she was faced with this illness, maybe death and leaving her daughters, and she was feeling a sense of failure, fear and sense of being out of control. She admits she knew nothing about ovarian cancer prior to diagnosis and was shocked that cancer could even occur there. When asked if she looked it up on the web, she commented she was very selective in the accumulation of information:

> Int So what were you thinking then? Did you look it up on the web?
>
> P5 Well it was pretty frightening, but I had to be sensible and not frighten the girls. My husband looked it up but he didn't say much. I didn't want to know too much, my head was just in a mess and like, well I was really scared and didn't want to see anything that was going to, well you know, tell me something even worse.
>
> (P4 para 19)

P5 admits fear and panic and is especially protective against frightening her daughters and herself. Even though she is convinced that death is a possibility, her instincts are still to protect her daughters from fear. Her uncertainty about the future and fear of the disease mean that she cannot bring herself to learn more about it, either by seeking information on the internet or discussing with her husband. She admits her "head was in a mess". Fear ensured she filtered information to what she could deal with. She was aware that she could not deal with any more frightening truth, uncertainty or threat. Her anxiety was considerable and she knew she would be unable to function if she became any more emotionally overloaded, with frightening facts that she was unable to control. She was a woman who normally managed her work, her family, and her life, but this was completely outside of her comprehension and comfort zone. If she was to function at all she needed to be working on a 'need to know' basis, and leave the technical/clinical information to the doctors. She was fully aware she had cancer and was prepared to do what was required, without knowing any more details.

The emotionally estranged self

The relationship with her husband was rather emotionally estranged and she discusses his detachment and failure to engage on a psychological level:

> Int How did your husband cope with it?
> P5 Hmm, as usual, didn't say much. He just doesn't want to know anything about things going wrong. When I had the erosion you know, he didn't want to know, just kept quiet, didn't ask or anything. He's not one for talking about things. But don't get me wrong, he helped around and did what he could and in his way well, he did what he could. I think he was worried, and well, couldn't cope you know. Probably didn't want to worry me and so we didn't talk about it at all really. Even when I was in hospital, he never mentioned cancer and even when I went to Cl, he treated it as though it were going to the dentist!
> Int Well how did he react when you were interviewed by Mr.X, told of the results and chemotherapy?
> P5 Nothing, he sat there and nodded and held my hand. The only thing he asked was how long would the treatment take. I was too choked to take everything in and after when we got home, I kept asking him what the doctor had said. He seemed to remember better than me so he had taken it all in, but he just didn't want to talk about it. And that was hard, I needed to talk about it, but I couldn't with the girls. Well I did tell them the basics you know it was cancer and I had to have the op and then chemo. But quite honestly, it was worse seeing them upset, I just avoided talking to them about it. The older girl M., she's 16 and I know she talked to her dad about it, but the younger one, C, she just didn't want to know. After, M said she did talk to C about things and she was OK. But C didn't even like coming to see me in hospital, only came once, made excuses and sent me cards.
> (p 5 para 20-21)

P5 discusses her husband as physically supporting her i.e. helping with the shopping and around the house and accompanying her to the hospital. But that appears to be the sum total of his support. She relates back to similar situations when she has been to hospital and he wouldn't discuss anything with her, 'he's not one for talking about things'. Her expectations of support from him are therefore low; she's not had any before in health situations and doesn't expect any now. Her statements regarding him probably being worried, concerned about coping and not wanting to worry her, suggest she understands and accept how he feels. She admits she could not bring herself to seek information on ovarian cancer and did not wish to go into detail with the consultants. She recognises and empathises with the fear and pain he is feeling and her rationale to explain his behaviour demonstrate her inability to accept her role change from that of care-giver, to care-receiver. Regardless of her diagnosis, she still excuses his inability to support her, to discuss treatment, prognosis and possible outcomes. Her criticism is veiled and somewhat tempered as she suggests "he's not one for talking about things. But don't get me wrong, he helped around and did what he could..." He had provided physical rather than emotional support; she was aware of his limitations and wanted more support, but was prepared for emotional deprivation.

During the consultation interview she commented on his failure of engagement with the doctor, only asking how long her treatment would take. The fact that she mentions this is significant as she relates she was too choked and upset to ask anything. She notes he only asked one question, suggestive that he should have asked more, more questions she wanted answering but couldn't ask. Here she does adopt the patient role and wants her husband to take control, find out the answers but recognises he fails. But she does recognise his assimilation of information during the interview and how he was able to fill in the gaps of information she had missed. But it was a detached engagement between them with him relating the factual data and subject matter but not wanting to comment on it, refusing to engage in empathy or subjectivity. P5 accepts his avoidance techniques but comments even though she recognises he didn't want to talk about it she really needed someone to talk to. Interestingly, she comments about informing the girls about the illness, and relates how upset she felt seeing them upset, "it was worse seeing them upset, I just avoided talking to them about it". She may be comparing her own reaction to that of her husband. Does she recognise that perhaps he found it too painful to discuss it with her, and having looked it up and discovered the prognosis, cannot discuss this reality. As a response to her husband's reaction P5 looked to friends for emotional support. She stated none of her friends knew about ovarian cancer, but she thought they had found information out following her diagnosis:

> P5 Yes I think they did but nobody said much, but they were really good you know, positive and kept me going. They took it in turns to take me for the chemo, and that was a new experience for them as well. And we tried to have a laugh, you know lighten things up and chat to other women there...
> Int Compare notes?
> P5 Well sometimes. Some didn't want to talk or they weren't well, and well they were with husbands and things. One was from W she'd had a hysterectomy too but for cancer in the lining

of her womb. She'd had breast cancer a few years ago and radiotherapy so she knew all about what was happening, but she said getting this was really frightening, thought it had come back, but the doctor told her it wasn't related, a completely new cancer and she thought that was better, you know that it hadn't come back. But I don't know, the thought of another cancer, really worrying. You'd think all these drugs would kill everything and it wouldn't come back?

Int Well every person is so different. How did you find going through the treatment?

P5 Not too bad really, they're all so wonderful at Cl., and you can always ask them anything, any worries or problems and they give you tips how to deal with side effects and everything. That's one thing when you finish, you really miss having them around.

Int You can always ring the help line.

P5 Yes I know but it's not the same. I usually ring my friends and I do keep in touch with S you know the one from the chemo? I know she didn't have the same as me but we did have the chemo together and she's good at giving advice, you know like tips and things; well my bowels were terrible and I tried what they said at CI but it didn't work and she said try X and I did and it was much better. Everyone's different as you say. And she was good about the wig, she said 'go straight away and get it organised' because I hadn't bothered, I was just so upset about everything and the thought of having to go and sort out a wig was just.....and I never dreamed my hair would come out so quickly, stupid really but I just had this idea that it would drop out bit by bit, I never thought it would all go at once and so quickly. That was awful and if I hadn't had the wig it would have been even worse! My friends took me to Liverpool and we got it there and then. But some of the women didn't bother with the wig at all, just wore scarves and it looked, well I wouldn't have liked it. Mine's just started coming through again, you know growing again, but it's all grey, I've never had grey hair, always coloured

> it, but now you have to wait for 6 months until the chemo gets out of your body before you can colour it.
>
> Int It looks really good. How about work?
>
> P5 Well I've been off sick, and I thought I'd have to leave but they've been really good and kept the job open so far. But I tell you what, when something like this happens, it makes you think, you know, about working and everything. The money was handy, not exactly a fortune but it was mine and certainly helps with the girls but H earns good money, he works at V you know in EP? But I think he liked my money coming in as well, helped with the holidays. Anyway I'm not going to go back full time, all those late nights and weekends and Bank Holidays, it's not fair and I want to be here with the girls, not that they want me here all the time, but the younger one needs me around, especially since all this. We've talked it over and H said ' do what you want, it's up to you'. So I've had a word with them and said I'll just do a couple of days to start with and see how that goes. They're happy with that.
>
> (P6-7 para 24-29)

The positive self

The essence of conversation changes here and P5 moves more into a positive mode, relating the support she had from her friends, the humour and socialising that occurred and the relationship in particular with another patient. The intimacy of the details that are discussed between the women and the acceptance and comfort P5 appears to display, is different to the discussions she had with her husband. She also reveals a confidence and ease she feels at the hospital chemotherapy centre, and mentions how she missed the staff when she completed her treatment. The bond she develops between her friends and the other patient is a very important support network, which P5 utilises as an information and advice source. The fear and 'alone' self she exhibited initially following diagnosis, has developed much more into a positive and realistic self. This follows as she commences her treatment and also as she becomes more accustomed to her diagnosis and prognosis, being able to discuss her own situation with other women and listen to their experiences, is something that P5 gained considerable support from. The report of the wig and the camaraderie of the fitting is one of 'girls together' rather than a husband and wife experience. She appears to accept he would never be part of that and is happy to accept the alternative support from friends, rather than insist her husband become involved. He also appears to have accepted that by choice, he wouldn't be expected to be part of this, never offering to take her for the chemotherapy and treating the appointments 'like a visit to the dentist'. P5 takes responsibility for her treatment just as she took responsibility for running the home and looking after the children. She also makes decisions regarding her future at work. Having thought carefully what this experience has meant to her, she made decisions to drop her hours to part-time and views her priorities differently; having discussed it with her husband she relates his comment, ' do what you want, it's up to you'. Again no opinion or influence from her husband, but in this instance P5 has already made decisions and 'discussing' it with her husband appears to be a formality only. Despite her mentioning he liked her money coming, she wasn't going to allow him to influence her decision making. She appears to accept his refusal to emotionally engage with her, "he just wants to close the door on the whole thing and forget all about it'. Whilst acknowledging this, she does state she would have liked to be able to talk to him about everything, have him share the experience and her worries, but accepts he will never change. His contributions were physical and not psychological, this she recognised and accepted, but his approaching the question of resuming sex did not receive a positive response in the list of P5 priorities. She did not disassociate her emotional worries from the physical, and was more preoccupied about the realities of disease recurrence; her irritation is evident as she relates his request, putting everything she has experienced in the previous months into perspective, with resuming sexual relations at the bottom of the list.

She demonstrates a perception of understanding her children's fears and worries, but is not prepared to make allowances for her husband. Whilst she accepts and exhibits understanding towards the daughter's attitude, her response to her husband is one of irritation and anger. She also appears to take control regarding the situation with her older daughter and the troublesome boyfriend. Whereas her husband does exhibit a degree of emotional response here, anger, she overrules him and makes decisions. From the initial beginning of her journey where P5 portrayed herself with a fragile dependence, frightened and desperate to discuss things with her husband, throughout the course of her experience she had grown into a strong woman, making important decisions and taking more control of her life. She reflects on this herself:

> P5 That's just him! To be honest, I get more from K and the others than I ever would with him. Yes I did want him to talk to in the beginning when it all first happened, because well, you know, I was so scared, didn't know what was happening and there was

> only him there and he'd been in with me to see Mr X and everything, but then K and the others rallied round and it was fine. They were great, really understood and bucked me up. And you can say things to other women that you just can't to men can't you? I said things to K that I'd never say to him, like I really thought I was going to die, in the beginning when they told me it was cancer, I thought that's it, I'm a gonner! You know you hear cancer and that's it. And K looked it all up, she's like that, she gets to know everything. But I said 'don't tell me anything awful, I can't stand it' and she didn't but she did tell me just little bits now and again and I was OK with that. And she's been great with M and all this business, she's had a word with her, but I don't think it's done much good as yet! I just think it might never have happened if I had been here to keep an eye on her myself.
> (p12 para 48)

She reveals her fears of death and her discussions with her friend K, intimate and real fears she could not discuss with her husband. Through these experiences the friend relationship developed into a strong and dependent bond, so much so that P5 had made the decision regarding welfare of her children in favour of her friends over that of their father:

> P5 I think just having the diagnosis before you have the treatment, you're in a state of limbo, knowing it's growing inside of you and there's nothing you can do, knowing it might kill you, you might die and not see the girls grow up, leave them without a mother. And that was an awful worry, who would look after them, couldn't trust their dad; don't get me wrong, he loves them I know that, but he'd just let them get on with it, he wouldn't think to do things. No I was thinking I'd have to ask K and the girls to keep an eye on them, you know pop in and just keep an eye. So that made me cry a few times and then in the middle of chemo I

> felt rough and it seemed to go on for ever, I just wanted it to be over, to get on with my life. I said to K my whole life is on hold, for months it's been operations and chemo, and feeling ill and doing nothing. It was awful. And I still have the odd wobbly moment, I look at the girls and still wonder if I'll ever be a grandma. Mind you that's tempting fate at the moment, with M and him, god, grandma's the last thing I need to think about! But then if I hadn't had this, perhaps she would still be Ok in school and thinking about going to university. I can't help thinking this is a sort of reaction from her, you know, to me being ill, her way of coping with it. But perhaps it isn't, perhaps it's just her and him coming along at the wrong time.
>
> (p13 para 50)

P5 has engaged in a lot of reflection through these experiences and in the process, dismissed the husband as a responsible person. His inability to support her emotionally is also extended to his inability to deal with the girls. P5 states 'couldn't trust their dad'; i.e. she couldn't trust him to support her in time of great stress and need, and she has decided if she wasn't there, he would be unable to look after his daughters properly. Moving on from this, she also displaced his responsibility onto the friends who had taken over his other role of looking after her during chemo. He had handed this over to her friends, and now she had delegated complete theoretical responsibility of her children to the people she trusted most:

> P5 Working long hours, evenings and weekends and then coming home and coping with everything here, it's just too much and no-one will help while I keep doing it all. I said they've all got to pull their weight including H, but might as well whistle in the wind as expect him to change. But there again he did help when

> I was in hospital and when I had the chemo; but it's just you have to tell him everything; he'll do it when he's told, but he just doesn't see it needs doing unless he's told. C said he's like the dog, needs training and talking to all the time, and she's probably right. That's one thing I've learned through all of this, if you don't look after yourself no-one else will. And people have just been so kind, you know, people you hardly know, like at work some of the part timers, sending me cards and things. You really get to know your friends, you know who you can trust and who'll help out. That's one thing that really shocked me, the way K and the others just took over, helped wherever they could and never expected anything, just came in and helped and bucked me up all the time. Nothing was too much for them, that's what you really call friends.
> (p14-15 para 53)

P5 is quite explicit in discussing her disappointment in her husband over the whole course of her experience, but she never mentions leaving him and is quite accepting in her attitude of knowing he will never change. Her poor expectations of their emotional supportive relationship may be tempered through habit and no desire for change. She talks of his financial and physical support and assumes the limits of that as being the totality of the relationship. The discussions between mother and daughter regarding the comparison of the husband's behaviour with the dog, appear to sum up his status in the family, but it appears to be of a more affectionate rather than critical comment. P5 found herself in a terrifying situation and recognising the support she desperately needed to get her through this experience was not going to forthcoming from her partner, sought it out from friends. She demonstrated a positive and proactive attitude and it worked for her. These friends took over her husband's role of emotional support and confidante, and she saw them as responsible for pulling her through. They demonstrated a level of friendship which she said 'shocked' her as she was the person who usually looked after everyone. This role reversal gave her an insight into friendship which she had never experienced previously and also gave her a new perspective on her life.

5.3. Summary of IPA

The process of IPA has revealed interpretation and misinterpretation, personal constructions, coping strategies and individual reactions such as anger, resentment, sadness and loss. The women and their families coped with diagnosis and treatment in unique individual ways and the voices of the women have told their stories. It was how they saw and understood events; the mental trauma of diagnosis; the experience of surgery and the trials of chemotherapy. By the time the women took part in this research, several months had passed, giving them time to reflect and compare the life they had now, with what it had been, prior to diagnosis. An insight into the psychological constructions of the women was uncovered. There is little doubt the women's experiences changed their views and concept of their life world and relationships irrevocably. Via IPA, the uniqueness of individual reflection and cognitive interpretation has been uncovered for each woman.

5.4. Phase 1 and 2 analysis comparison of findings

Thematic analysis (TA) and the questionnaires in pilot phase 1 indicated the *process* or common themes the women experienced, whereas IPA gave more *content,* a cognitive insight. The contribution made by the utilisation of TA, in conjunction with IPA was that of a more developed and richer analysis, on what the experience of ovarian cancer really meant to these women detailing the breadth and depth of the issues relating to the experiences of the women. Phase 1 described the experiences the women underwent. Phase 2 was different, instead of shared descriptions, it examined in detail the aspects of self - *worried, pre-diagnosis, dependent, helpless and the striving towards normal*, as the women progressed through the disease trajectory. The IPA cognitive process obtained in-depth, individual phenomenological accounts; whilst super-ordinate themes were similar for the women, the sub-themes were unique to each woman and her personal story. The differences in perspectives demonstrated by the different data interrogations of phase 1 and phase 2 are evident and summarised in tables 5.2 and 5.3 from phase 1 and table 5.4 from phase 2. The differences in the approach and findings are discussed in chapter six.

Table 5.2. Phase 1 – questionnaire findings

Item	**N women**
Contraceptive pill	3/15
Hormone replacement therapy	8/15
Recollection of signs and symptoms prior to diagnosis	
bloating	9/15
bowel problems	7/15
abdominal pain	5/15
back pain	10/15
urinary symptoms	12/15
Dissatisfaction with time taken for GP diagnosis expressed	11/15
Satisfaction with time taken for GP diagnosis expressed	4/15
No prior knowledge of ovarian cancer	13/15
Information seeking on the internet post diagnosis	2/15

Table 5.3. Phase 1 - themes produced via TA

Theme	Comments	Number of women	Time range
Physical signs and symptoms	Bowel changes urinary changes vaginal bleeding pain increase in girth dyspnoea	13/13 experienced 3 or more symptoms	1 week to >12 months prior to visiting GP
GP interactions	Non examination Not taken seriously Not referred Repeatedly given antibiotics Referred for 'wrong' investigations	8/13 reported satisfied with GP treatment 5/13 were dissatisfied with GP treatment	Stated 1-13 visits up to 12 months prior to diagnosis Varying time scales for consultation
Hospital experiences	Not as bad as expected Relieved to have surgery All agreed to have chemotherapy	13/13 pleased to get on with treatment	8-10 month period From surgery to completion of chemotherapy
Family/partner interactions	Discussion of diagnosis and prognosis between spouses; some women refused to discuss, others wanted transparent relationship	10/13 women thought their partners had looked up ovarian cancer on web but didn't discuss with them 3 husbands had been on web and did discuss with wives	From diagnosis through to interview with researcher
Personal psychological interpretations	Most were positive about future Most reflected on negativity of not going to doctor earlier Emotions of denial, anger, fear, sadness expressed by most women	11/13 positive about prognosis, 3/13 possibly unrealistically positive 2/13 realistic in that prognosis palliative only	From pre-diagnosis to interview with researcher

Table 5.4. Phase 2 - themes produced via IPA

Superordinate themes	Sub themes
1. Impact of diagnosis of ovarian cancer	1.1 Denial 1.2 Fear 1.3 Powerlessness 1.4 Isolation 1.5 Refusal to accept
2. Self Identity	2.1 Losing face 2.2 Concern what others think 2.3 Denial of being different 2.4 Sense of failure 2.5 Loss of attractiveness
3. Self - partner/family	3.1 Sadness 3.2 Fear 3.3 Comparison with other family members who have had cancer and died/survived 3.4 Deflection 3.5 Anger and resentment
4. Coping Strategies	4.1 Positivity 4.2 Denial 4.3 Reassurance (with treatment and from medical staff) 4.4 Acceptance 4.5 Fatalism 4.6 Helplessness
5. Search for meaning – 'why me'?	5.1 Focus on normality –'good health' 5.2 Denial 5.3 Blame 5.4 Anger 5.5 Fatalism 5.6 Resentment
6. Future self; Transition from 'Old' to 'New' self	6.1 Sexuality 6.2 Normality 6.3 Return to wellness 6.4 Control of self and thus disease 6.5 Fear of recurrence 6.6 'Live for the moment'

CHAPTER SIX

Discussion

6.1. Introduction

The research aimed to qualitatively explore what a diagnosis of ovarian cancer meant to women, from a phenomenological perspective. A phenomenological perspective has been used in a number of ways in research (i.e. Giorgi, 1970, 1994, 2000; Moustakas, 1994; Smith, 1996; Smith, Jarman and Osborn, 1999). For example, Colaizzi's (1978) phenomenological perspective, is influenced by Giorgi's (1970) descriptive pre-transcendental Husserlian phenomenology whose aim is the identification of the phenomenon based upon convergence of accounts.

The framework for this thesis has been as Giorgi (2006) emphasises with the important adoption of a disciplinary attitude, together with philosophical Husserlian ideology, to employ phenomenological theory. Thus if a psychologist engages in phenomenology, then psychological knowledge should also be incorporated into the framework. Giorgi suggests that this adoption of 'expert' disciplinary knowledge brings a greater understanding and sensitivity to the analysis. Importantly, Giorgi emphasises the question of validity and reliability of findings, disputing the suggestions of Arminio (2001) and Driscoll (2004), in the use of 'judges' in the verification of findings. Giorgi (2006) however believes that from a phenomenological perspective, such strategies are misguided. He suggests that requesting several other 'experts' to review the work could at best suggest some type of 'face validity', but the procedure could not function to ascertain 'genuine validity'. He clarifies this by stating new findings from the work are justified on the basis of all new data collected, not just on past experience of experts. For example, in this thesis the experiences of the women are unique and analysis by others (experts) may not necessarily contribute. Giorgi suggests that phenomenological theory properly applied can result in robust findings, particularly when utilised with a disciplinary perspective, such as psychology. He states the 'ordinary person' will be unaware of these procedures and that any methodological or theoretical verification (by the participant) would not contribute to understanding. Furthemore, Giorgi purports that disciplinary perspectives will contain terminology or theory, that require a level of expertise to understand. As participants may not have this knowledge, such validation would be negligible.

As stated, the underlying theoretical perspective throughout the present research has been that of constructivism and phenomenology. Maturana (1992) views existence consisting of a continuum of structural change in relation to the medium it exists in (society/environment/disease). This 'history of accommodation' as it is termed is without meaning until a 'disintegrating' event occurs. In this research this women had developed ovarian cancer, an event that threatened their reality (their autopoietic, self-creating, self-sustaining structure). The women's perceptions demonstrated adaption, reflecting the theories of von Glaserfeld (1995) in that human perception is adaptive, evolving to help individuals survive. The women in my research evolved, adapting to cope with disease progression and challenging treatments. Von Glaserfeld incorporated Piaget's work (1984, 1995) in advancing the theory of cognitive adaptation, arguing that assimilation and accommodation are constructivist concepts. Assimilation is constructivist in that it entails adapting information to individual experiential understanding. In the present research, women slowly assimilated what the reality of what their disease meant to them and their families. This was an evolving cognitive process as disease details (constructs) became evident; accommodation took place in various ways, for example, by wanting more control of events, recognising some behaviour as unacceptable (i.e. patient/doctor interactions), or developing psychological coping strategies to cope with the disease. For social constructionists, language is a crucial determinant in how people explain their world and the nature of their experiences. Gergen (1991) discusses the role of language culturally in power relationships; within this thesis, language was critical, within the communication process it was found that *interpretation* of what was expressed (spoken word) or not expressed (not spoken) was variable and related to the *reality* the woman chose to adapt .

In this research, data was collected in 2 phases. The phase one pilot focused on an essentialist framework to explore individual experiences, meanings and realities. Phase one produced considerable rich data on the physical signs and symptoms, interactions and treatments, this provided themes of importance to the women participants. Phase one analysis indicated that further research from a *dynamic cognitive* perspective on the psychological processes and interpretation, would provide deeper meaning and perspective. Lessons learnt in phase one and a critique of the method will be discussed later in this chapter.

The phase one research methodology utilised thematic analysis and provided the basic *process* of common themes the women experienced, whereas the interpretative phenomenological analysis (IPA) utilised in phase two provided more *content* or depth and cognitive insight. Phase one described the experiences the women underwent. These were factual descriptions of their individual journeys and demonstrated the similarities between the women. They all underwent surgery and chemotherapy and had a shared understanding which was evident in the thematic analysis. Phase two was a refined process, with a new participant sample, designed to focus on understanding, meaning, cognition and interpretation of the experiences of the women. The results from both phases provided rich and complex, yet different perspectives. Together, these gave an insight into the experience of women with ovarian cancer. Lessons learnt in phase two and a critique of the method will be provided later in this chapter.

In summary, from the findings of phase one, data concerning participant perspectives on ovarian cancer was obtained. However, the in-depth phase two interpretive phenomenological analysis enabled myself as researcher to engage in depth with both the research process and the participant. Within IPA researcher reflexivity is important in attributing meaning. Analysis of individual accounts facilitated progression from the descriptive thematic analysis of phase one, to an interpretative analysis of each individual case (Smith, 1995; Smith, Jarman and Osborn, 1999) in phase two.

6.2. Pilot phase one

6.2.1. Findings

Phase one findings were descriptive and based on a pre-interview questionnaire and a one to one interview, which was subjected to thematic analysis. It became clear during the research that the women had a lack of knowledge regarding ovarian cancer, prior to diagnosis. Once diagnosed, the signs and symptoms were understood by these women. Diagnosis *explained* the increasing girth, the bowel habits, the urinary problems and pain. Given plausible explanations, helped understanding. It was the fear of *not knowing* that was difficult. This research has demonstrated the lack of knowledge many women had in regard to power, negotiation and basic health care rights. A reflective process had been used as the women made their journey through the medical system. During interviews women retrospectively commented that they would certainly have approached GP consultations differently. Despite increasing and in certain cases, quite distinctive signs and symptoms, the women generally were apprehensive of wasting the doctor's time. Wileman et al (2002) and Rosendal et al (2005), suggest this is due to patients being worried about being labelled as a nuisance or hypochondriac, and this appear relevant to the women in the current research.

The research found that for months or even years the women experienced various signs and symptoms. The explanations of signs and symptoms given by the women were complex and multifaceted. Listening to the women, they all stated that they only went to the GP when symptoms were of major concern, one stated "she didn't have a season ticket", and the thought of having internal examinations was not an inducement to attend. This situation of presenting with acute symptoms and perceiving that they were being told sometimes 'dismissively' that nothing was wrong, was reinforcement not to attend again. For some women, the next time they did request GP opinion, it led to emergency hospital admission.

Research suggests that GP's only see a case of ovarian cancer infrequently (Kirwan, et al 2002). Redelmeier (2005) suggests that patients can only describe what they *know* and verbalise what they *understand* about their symptoms. It is the doctor who ultimately decides *whether* and *how* to act, based on the information provided, their own interpretations and other external and internal factors.

The recollections of the women in relation to referral are distinctive in that eight women (8/13) were diagnosed at an early disease stage and perceived that they had a GP who listened, examined and appropriately referred them to gynaecology. Some of the women who were referred early by their GP's recollected that they were also undergoing other treatment at the time, with tumours discovered by default. For example, one woman was having regular appointments for abnormal smears, another woman presented with abdominal swelling thinking she was pregnant and another woman was undergoing hormone therapy with regular appointments. Thus, for these women the ovarian cancer may have been discovered whilst undergoing other investigation. This contrasts with the women who believed that their diagnosis was delayed, one woman complained of frequency and pain on micturition.

This patient recollected visiting her GP six times, over six weeks, with recurrent and non resolving symptoms, prior to referral. Another woman openly admitted to fear of exclusion from the practice if she complained about her GP. This may have been related to the woman thinking that she may not be able to register with another doctor. Understanding patient rights and how a complaint would have been dealt with may have made a difference to this woman. One woman recollected that she had been referred by a locum GP and expressed little confidence in her regular GP. She stated that on her post operative visit to her regular GP, he informed her that he had not had any patients with ovarian cancer before. This may have influenced her stated lack of confidence in her GP. However, it must be recognised that these retrospective recollections may have been influenced by subsequent experience, knowledge and treatment since diagnosis.

6.2.2. Method critique

A critique of methodological issues of relevance to both phases will be provided later in the chapter, this section will review phase one methodology. Braun and Clarke (2006), view thematic analysis as a process of minimally organising data into rich sets, that does not have an allegiance to a specific epistemological position in the same way that other methods, such as narrative analysis or grounded theory do. Some research suggests that a lot of qualitative analysis is essentially thematic, but claimed as something else, such as discourse or content analysis (Attride-Stirling, 2001; Meehan et al, 2000; Boyatzis, 1998).

Data was analysed using thematic analysis (TA), a widely used qualitative analysis technique in psychology (Braun and Clarke, 2006; Boyatzis, 1998), this produced themes regarding the women's perceptions of their disease. The process of thematic analysis was made explicit in the methodology, as suggested by Braun and Clarke (2006). Standards for undertaking a good quality thematic analysis were adopted to ensure research validity was enhanced, the standards reflected Braun and Clarkes (2006) criteria for quality thematic analysis. The assumptions and approach to thematic analysis were clearly outlined and there was a good fit between the method and analysis. The language and concepts were consistent with the epistemological position of the analysis. As a researcher, I recognised that I was active in the research process and kept a reflective diary of my thoughts, feelings and recollections. The data was transcribed to an appropriate level of detail, and the transcripts have checked against the tapes for accuracy. Each data item was given equal attention in the coding process. Themes were not generated from a few examples; the coding process was thorough, inclusive and comprehensive. All relevant extracts for each theme were collated. Themes were checked against each other and against the original data. Themes were internally coherent, consistent, and distinctive. Data were analysed and interpreted, rather than just described. Analysis and data mirrored each other and the analysis developed a story about the data and topic. A balance between analytic narrative and illustrative extracts were provided.

Thematic analysis did highlight similarities in experience such as missed symptoms and misinterpretation. However it was noted that although the thematic analysis provided breadth it did not provide any depth or substance to the women's stories. Themes were identified and quotations used to illustrate issues, but the meanings and richness of the women's stories was not developed. In addition, the pre-interview questionnaire was found to be unnecessary. Upon reflection, this data could have been obtained during the interview. The one benefit of the questionnaire was that it did keep the interview shorter as some basic data, for example on signs and symptoms was obtained via the questionnaire. By enabling the participant to initially record their signs and symptoms in the questionnaire it appeared to facilitate their discussion at interview as they had already had time to reflect on these issues.

6.3. Phase two

6.3.1. Findings

Smith and Osborn (2003) state in IPA "there is no attempt to test a pre-determined hypothesis of the researcher; rather is to explore, flexibly and in detail, an area of concern' (p 53). Experience of ovarian cancer is individual and complex. Interpretative phenomenological analysis (IPA) provided depth and richness, via cognitive insight. For example, the versions of *self*, important to each woman, such as the sexual self, the lonely, helpless or frightened self, that women disclosed at interview. These higher ordinate themes revealed areas of lived experience, such as fear, loneliness, loss of attractiveness, fatalism and denial which, because may be unsaid and not addressed in health psychology research, it is as important to recognise these 'unspoken realities', equally as much as the 'expected' or 'predicted' clinical themes.

verbalised by the women (Brocki and Wearden, 2006; Smith et al, 1999). In this research, IPA highlighted the hidden agenda that women were trying to live with, alongside their diagnosis; it gave them the opportunity to express the complexity of feelings and emotions of dealing with sometimes multiple losses.

Having time to cognitively analyse these experiences, the women were able to construct a scenario of how their 'new life' would reconstruct 'reality' for them. Some were evasive, with denial and a longing to return to 'normality', yet the identification and construction of this 'normality' was a very different one from the reality in which they now existed.

A crucial issue throughout this thesis and in phase two analysis is the women interpreting the symptoms they experience and their interactions with others including the medical profession to create their own 'reality'. The way in which 'reality' was interpreted, related to responses and actions in help seeking and medical advice, at the varying disease stages. In addition, interactions with others, such as family, friends, colleagues and the medical profession were equally important.

The misinterpretations, misunderstandings and cultural distinctions in the use of 'specialist knowledge' by the women, are examples of how knowledge systems are accumulated and utilised in different ways, for example by patient and doctor. It demonstrates how knowledge can be rationalised and filtered to become more acceptable to individuals and also partners to produce cognitive equilibrium.

It was at interview that the women were given time to relate their interpretations of how they'd viewed their cancer experience. They selected to highlight issues and periods they saw as important and were given the opportunity to develop themes and opinions interpreting this subjective reality. For the women in this research, who had established their own reality about their disease, adopting the 'medical model' as they journeyed through treatment often created inner conflict. Misunderstandings about prognosis, interpretation of 'palliation', fear of 'truth', denial to family and from loved ones, needed considerable assimilation for cognitive equilibrium to be achieved. In several cases, quite elaborate constructions of an alternative reality were created by the women and/or their partners, in order to sustain each other through a very traumatic period in their lives.

6.3.2. Phase two method critique

A critique of methodological issues of relevance to both phases will be provided later in the chapter, this section will review phase two methodology. Phase two examined the experiences of five women with ovarian cancer, via individual semi-structured interview and analysed using IPA (Smith, 1996). Each woman presented different perspectives and issues in relation to the psychological construct of 'self'; the 'worried self', 'pre-diagnosis self', 'dependent self', 'helpless self' and 'striving towards normal self'. Individualised phenomenological accounts were reflected through the IPA cognitive process, and whilst certain superordinate themes could be generalised across the population, the sub-themes meant very different things to each women. The IPA framework provided a rich, deep and meaningful analysis. IPA is not intended to analyse large data sets (i.e. Brocki and Wearden, 2006 review numbers in multiple studies; Smith, 1996, with 1 participant; Jarman et al, 1997, with 5 participants; Osborn and Smith, 1998, with 9 participants) as during the coding of a large number of interview transcripts, subtle meanings may be lost.

The methodology for phase two was based on incorporating a cognitive, linguistic and hermeneutic framework, via IPA analysis (Smith, 1996a). Smith and Osborne (2004), recognise the power of cognition, phenomenological experience and verbal reports in the reporting of and predicting of subjective experience. Whereas thematic analysis had effectively outlined constructivist themes in pilot phase one, the double hermeneutic dynamic process had not been developed. Hermeneutic phenomenologists' specifically recognise the role of the analyst as crucial in the interpretation and framing of data analysis (Giorgi 1995, 1970; van Manen, 1990), in order to understand the participant's reflection and structured inference of their experience.

To ensure research qualitative validity was enhanced in phase two, quality standards were implemented. The standards reflect Braun and Clarkes (2006) quality criteria for thematic analysis, adapted to be specific to IPA. In addition, the research methodology incorporated the recommendations for qualitative research of Smith and Osborne (2003, 2004) and the British Psychological Society guidelines (BPS, 2008).

Although IPA is phenomenological in that it aims to explore individuals' personal perspectives of an event or a state, proponents of this approach take the view that one cannot do this directly or completely. In a Heideggerian sense, this assumes dependency upon the conceptions of the researcher in interpreting individual experience. The aim of IPA, as Jarman, Smith and Walsh (1997), state "to capture our concern with exploring individual participant's perspectives, whilst also recognising the research exercise as a dynamic process, to some extent guided by the interests and concerns of the investigator" (p.141). Central to IPA, is the researcher's own interpretation of meaning elicited from the analysis of the participant interview. Within health care, this relates to a "belief in and concern with, the chain of connection between account, cognition and physical state" (Smith, 1996, p. 265). The aim of IPA as Jarman, Smith and Walsh (1997), state is "to capture our concern with exploring individual participant's perspectives, whilst also recognising the research exercise as a dynamic process, to some extent guided by the interests and concerns of the investigator" (p.141). Smith (1997) suggests that IPA research is 'a two stage interpretation process, or double hermeneutic'. In this way, Smith (1997) suggests that IPA has an intellectual link with hermeneutics, with the interpretation of ideas and understanding, both from researcher and participant perspectives being key issues. Through this didactic, it has been possible to exemplify the theory with practice. By utilising IPA, the meaning of the experience of ovarian cancer was explored in depth. Throughout the primary and higher level evaluation of the interviews, the fears, denials, anger and despair of each woman became evident. As a researcher, IPA has enabled my interpretation, from a health psychology perspective, of the ‘reality’ between verbalised narrative and meaning, possibly too painful to become explicit linguistic statements (Smith, 1997; Brocki and Wearden, 2006).

6.4. Summary of phases one and 2

The research utilised the analysis methods of thematic analysis and IPA in order to understand the complexity of ovarian cancer. Both of the methodologies are phenomenological and have been extensively detailed in chapter 3. The first phase pilot, aimed to gather information on similarities and differences in the experiences of women, via constructivism and utilised a pre-interview questionnaire and thematic analysis. Data collected related to physical signs and symptoms, diagnosis and treatment. Thematic analysis provided a means of developing broad based themes that could be generalised. Thematic analysis had limitations in that it did not provide depth of understanding. In addition, upon reflection the questionnaire completed prior to interview was extraneous. It provided useful background prior to interview and reduced the interview length, yet data obtained could have been gathered at interview. In addition, the interview discussion and issues brought up by the women, may have been influenced by the completion of the pre-interview questionnaire. Phase two was developed to a more specific idiographic level; it adopted the double hermeneutic of Smith (1997). Phase two produced a richer, more meaningful analysis in relation to the cognitions involved in the experience of ovarian cancer.

6.5 The research findings in relation to the narrative review

In relation to the narrative review, the broad themes identified in the phase one thematic analysis and questionnaire and the phase two analysis, in relation to signs and symptoms were similar. This indicates that there is a problem for women in timely identification of signs and symptoms, with a resultant need for the consideration of public education needs in relation to ovarian cancer; this is discussed in the research recommendations.

The narrative literature review highlighted similar issues pertinent to this research, and demonstrated the importance of ensuring quality in qualitative research. Several papers were rigorous in their attention to validity and theoretical perspective, one (Swenson et al 2003) admitted too much emphasis had been placed on the theory, design and application, which subsequently restricted the richness of data. They stated future data collection would be undertaken differently.

Power et al (2008) states that their potential subjects were identified through an oncology clinic, without further expansion regarding eligibility criteria or sampling criteria (N=30); a more informative description is provided by Ziebland et al (2006) who discuss a maximum variation sample with variation in geographical area, age range, treatment and survival time discussed. Recruitment is discussed, with no reference to eligibility or exclusion criteria provided. Similarly, Acyuz et al (2008) stated that participants were recruited in a clinic, but provide no information regarding sampling technique or eligibility criteria and states recruitment continued until data saturation was reached (at 19 women). Pilkington and Mitchell (2004) and Elit et al (2002), with samples of 14 and 21 respectively are the only studies that provide a detailed description of sampling, including eligibility, exclusion criteria, time period and recruitment method of recruitment.

Zeibland et al (2006) Elit et al (2002) and Power et al (2008) specifically looked at ovarian cancer, whilst Pilkington and Mitchell (2004) and Acyuz et al (2008) looked at all gynaecological cancers. Six studies incorporated face-to-face interview into the research design, sample size ranged from 14 (Pilkington and Mitchell, 2004) to 43 (Ziebland et al, 2006). Numbers recruited reflect the nature of the disease and possibly difficulty in recruitment being an international problem.

Themes

The themes identified in the studies reflected similar aspects of my research and highlighted the lack of knowledge and insight about ovarian cancer from the women themselves. Findings reported delays in diagnosis, effects on family life, doctor/patient relationships and loss of control (Elit et al, 2002; Ferrel et al, 2003; Power et al, 2008; Smith, 2008). The findings of Zeibland et al (2006), are reflected in my research, with some women not recalling being involved in the decision-making process; some asking questions and agreeing to doctor recommendations even if unsure and some recognising they had taken control of their lives.

6.6. Discussion of research considerations

This section will discuss issues of relevance to both research phases.

6.6.1. The development of phase one into phase two

Phenomenology, as postulated by Husserl (1925) focuses on the experiences of individuals, within particular contexts, at particular times. Leonard (1994), states, "The ultimate criterion for evaluating the adequacy of an interpretive account is the degree to which it resolves the breakdown (in human affairs) and opens up new possibilities for engaging the problem" (p. 60). The central aim of phenomenology is to capture as closely as possible the way a phenomenon is experienced by the individual (Giorgi, 1970, 1995). A phenomenological perspective has been used in a number of ways in research (i.e. Giorgi, 1970, 1994, 2000; Smith, Jarman, and Osborn, 1999; Smith, 1996a; Moustakas, 1994; Colazzi, 1978). Pilot phase one provided a phenomenological interpretation of the women's experiences that highlighted similarities and differences However, upon reflection thematic analysis, did not impart the level of individual psychological insight that was required to provide depth of meaning (Smith, and Osborne, 2003, 1997). Upon reflection of such quality concerns, it was decided for phase two to use a more contextually interpretative analysis of individual cases (Smith, 1996a; Smith; Jarman, and Osborn, 1999).

By utilising the double hermeneutic (Smith, 2007), interpretative phenomenological analysis (IPA) uses in-depth, individual qualitative analysis (Smith et al, 1999; Bannister et al, 1994). IPA does not seek to claim objectivity, as other methodologies may do via detailed formulaic measures. Smith et al (1999), emphasise that the focus is "Themes and connections available within the text, rather than attempting to find instances that would fit a particular pre-existing theoretical, viewpoint" (p 231). IPA encourages in depth analysis of small numbers (Smith 1996a; Smith, 2004; Brocki and Wearden, 2006). IPA does not contribute to theory generation, as grounded theory does. It is however, increasingly used in the field of health psychology research (Smith, 1996a, Smith et al., 2003, Smith, 2004), and provided a theoretical framework, for the exploration of the experiences of women with ovarian cancer, from a psychological perspective.

6.6.2. Sample size

Sample size provided some limitations due to the incidence rate of the disease, inclusion criteria and willingness of women to participate. Women with other cancers could have been included in the research to increase participant numbers. However, the research aim was to explore in depth, the experiences of a particular group of women with ovarian cancer, at a micro-level, not to generalise necessarily to other groups (Smith, 1996; Smith and Eatough, 2006, 1999). Furthermore, there is a growing consensus in qualitative research towards smaller sample sizes (Smith, 2004). Smith et al (1999) and others (Brocki and Wearden, 2006; Reid et al 2005; Smith and Osborne, 2003,) suggest that *less* is in fact *more* in IPA, a challenge to traditional qualitative theory. IPA supports the philosophy that "From an idiopathic perspective, it is important to find levels of analysis which enable us to see patterns across case studies, while still recognising the peculiarities of individual lives from which those patterns emerge" (Smith et al, 1999, p 224,). Within IPA, each case is unique; deviant cases and data saturation are not sought, as each individual case is unique and subjected to in-depth analysis. Amassing large quantities of similar data is viewed as unnecessary, as the aim is to establish *individual* accounts of phenomenological experiences. Thus the specificity of the *lived experience*, uncovered via IPA, for the five women, was deemed to have a strong and defendable theoretical standpoint. As Brocki and Wearden (2006) state:

> "In IPA the aim is to select participants in order to illuminate a particular research question, and to develop a full and interesting interpretation of the data. Grounded theory, on the other hand, uses theoretical sampling, which aims to keep collecting data in the light of the analysis that has already taken place, until no new themes are emerging". (p 95)

6.6.3. Data collection

Leonard (1994), states, "The ultimate criterion for evaluating the adequacy of an interpretive account is the degree to which it resolves the breakdown (in human affairs) and opens up new possibilities for engaging the problem" (p. 60). In relation to Miles and Huberman's (1994) points on data authenticity, plausibility and adequacy, within this research participants provided in-depth descriptions about their experience of ovarian cancer, women were all given the opportunity to ask questions and add in any way they wished if they felt something was not covered during the interview.

The study of individual human experience from a psychological perspective is more suitable to the utilisation of qualitative research, specifically individual in-depth interviews. The interview is a means of reconstructing events and personal experiences (DiCicco-Bloom and Crabtree, 2006). Within this research, individual experience in relation to ovarian cancer was verbalised during interview; the IPA interview analysis provided much greater depth and richness than the phase one thematic analysis.

Methodological concerns related to data collection are discussed by Denzin (2001); Meyrick (2006) and others, for example Smith and Osborn (2003) discuss the semi-structured interview as the ideal method for IPA, Alexander and Clare (2004) concur in viewing the participant as 'expert' with the interview the best method of capturing data. Variations have been used, Murray and Harrison (2004), used face-to-face interview, in conjunction with email interview; and Alexander and Clare (2004), used interview in conjunction with written participant narrative. Reynolds and Prior (2003), analysed both interview transcripts and written narratives, but expressed concern that the participants may have been trying to answer as the interviewer wanted, rather than being spontaneous at interview. Reynolds and Prior, suggest that dual data collection is merely duplication, with one method affecting the other. This may have been the case in pilot phase one, with using both the questionnaire and interview.

Brocki and Wearden (2006) and Smith and Osborn (2003), discuss the use of the interview schedule and state few researchers *describe* the process and few give examples of prompt questions and suggest that it is difficult to judge the quality of the interview, without a formal schedule but caution that this should be utilised as a guide only. In both phases, a semi-structured interview schedule was used; in phase two, movement away from the schedule was flexible to ensure that any unique or novel data was captured

6.6.4. Assessing data quality

Identifying quality in qualitative research can be problematic. Potter and Hepburn (2005), debate if qualitative data is objective. For example, Dixon-Woods et al (2007), in discussing appraising qualitative research for inclusion in systematic reviews compared expert opinion; a UK Cabinet Office quality framework and the critical appraisal skills programme tool (CASP). Six researchers assessed twelve research papers. Dixon-Woods et al reported that using structured instruments made reviewers more explicit, about their rationale but concluded that structured approaches may not produce greater consistency of judgement regarding the inclusion of qualitative papers in a systematic review, with further research needed to evaluate how best to incorporate qualitative research.

6.6.5. Data validation, trustworthiness and cross validation

The question of validity in any qualitative data collection and analysis remains an important but somewhat controversial factor (Henwood and Pigeon, 1992; Smith, 1996; Stiles, 1993). Silverman (2006, p 282) suggests that for reliability, transparency in the process of the research design and analysis is important. Larkin and Griffiths (2002), report that data validity depends on the *level of transcription and the interpretative* nature of note taking. They suggest that in qualitative research "data is always a selective account of *the event itself*" (p308). Holt and Slade (2003) suggest that the validity of qualitative data should be considered by the appropriateness of the illustrated themes to similar situations. This is different to IPA, which does not aim to achieve a representative sample (Smith, 1999). The subjective nature of the present research requires highlighting as analysis and interpretation evolved through my own personal relationship with the data. This unavoidably necessitated introducing my own subjective beliefs and views which Smith (1996) acknowledges as inevitable.

Yardley (2000) suggests validity should be sensitive to the research context, with rigour and transparency. Smith (2007) suggests that whilst Yardley's suggestion for validity is useful any interpretation of this is subjective and will have an impact on the incorporation of theory and data. Validity enhancing techniques as advocated by Miles and Huberman (1994); Silverman (1993); Yardley (2000) and others (Larkin and Griffiths, 2002; Smith and Osborne, 2003; Stiles, 1993 and Yin, 1989) were incorporated into the present research.

To ensure robustness, qualitative validity and reliability were considered throughout the research process; for example by piloting the pre-interview questionnaire and developing the semi-structured interview schedules in collaboration with my supervisor. In addition, my supervisor reviewed and discussed the methodology and methodological assumptions. Participant validation was not sought. A theoretical reason provided by Giorgi (2006) and Merleau-Ponty (1964) for the participant not being an analysis verifier, is that the individual who *experienced* the event, may not be the best judge of the *meaning* of the experience. Therefore when a researcher presents phenomenological findings to a participant, they are requesting the individual to confirm lived experience, yet many participants may not be aware of the *meaning* of their experience. As Giorgi (2006) suggests, the application of phenomenological method is a time consuming, painstaking procedure. Skilled researchers have expertise and knowledge gained via their discipline, making them better verifiers of the meaning of their data, than external judges or the participants themselves, who may not understand the research context, language used or theoretical constructs (Giorgi, 2006). Furthermore, had participant validation been congruent with the theoretical framework, due to the emotional nature of some participant admissions during the interview, participant validation may have caused distress to some individuals; I would have viewed this as an ethical issue (APA, 2002; BPS, 2004).

Yin (1994) supports methodological validation with the use of an audit trail. This method is advocated in IPA (Smith, 2003), the rationale being that any qualitative method is to some extent subjective, therefore individuals should validate by considering the robustness and transparency of the methodological process. Triangulation is recognised as an effective validation tool (Miles and Huberman, 1994; Braun and Clarke, 2006); Silverman (2006) criticises triangulation as potentially flawed, as each method utilised in data collection relies on the same reliability factors and may be equally inconsistent i.e. the researcher may be poor at recording interviews and inaccurate in analysing questionnaires. Furthermore, the accuracy of one approach, does not cancel the inaccuracy of another approach and the aggregation of data, even within a similar theoretical perspective may fail to produce an overall truth. In other words, each method may be inconsistent or unreliable and Silverman emphasises the importance of *understanding* and not *judging* the truth. Smith (1996) suggests that IPA is a valid tool in health psychology that can triangulate individual physical condition (illness) with linguistic and cognitive response. Within the present research, triangulation of data from both research phases and the qualitative research discussed in the narrative review, indicated similarities and to some extent convergence in signs and symptoms and in some experiences, hopes and fears.

Silverman (2006) cites problems with individuals interpreting things differently and highlights the importance of generalisability and selectivity in sampling, as effective in developing empirically valid findings. Miles and Huberman (1994, p. 173) state, "we would like to know something about the relevance or applicability of our findings to other similar settings". However, Denzin (1995, 2001) and others (i.e. Smith, 2007, 2004; Smith and Walsh, 1997) suggest that generalisability is to some extent inappropriate in qualitative research given the number of participants generally involved. In terms of generalisability it has been suggested that it is generally inappropriate for qualitative research (Denzin, 1995, 2001) and inappropriate to IPA specifically (i.e. Smith, 1996a; Smith et al, 1997). Within this research, homogeneity was sought and purposive sampling was utilised, as I was interested in the experiences of women with a diagnosis of ovarian cancer. IPA focuses on individual 'lived experience' and is not necessarily generalisable to other populations (Brocki and Wearden, 2006). Therefore, I undertook this research to explore the experience of women with a particular illness, from a specific area of the UK, at a specific time point. I anticipated that the results, whilst providing valuable information of possible use to other researchers, would not necessarily be generalisable to another population, region or culture.

6.7. Study limitations

GP perspective

It may be seen as a limitation to the study that the GP's were not interviewed during this research. Patients gave their personal interpretations of GP interactions, but this was distinctly from a receiver perspective. If the researcher was to undergo a similar study, interviewing the GP's would certainly be a consideration to provide another dimension. The findings of this research have been presented to several GP forums and GP's recognised that a national initiative to educate on ovarian cancer is important. It would be interesting to audit the future referral patterns of GP's following the outcomes of women whose diagnosis was eventually confirmed as ovarian cancer. As Dempsey and Bekker (2002) suggest that GPs may refer a greater number of patients to fast track or emergency admissions, if there was even a small risk of 'missing' a future diagnosis.

Participant recruitment

As discussed in the methodology chapter a number of women declined to take part in research phase one or 2. This was possibly due to symptoms of advanced disease, poor prognosis or psychological reasons. These women were not contacted to discuss non-participation as I felt that ethically, having to justify non-participation may have been difficult for the women (APA, 2002, BPS, 2008). The number of participants recruited in both research phases was relatively small, but appropriate for a pilot and for IPA analysis. Phase one was a pilot aimed at providing an overview of the similarities and differences, on the *breadth* of the experiences of women with ovarian cancer. To provide greater breadth, future research could develop a quantitative questionnaire, with a large national sample. Phase two aimed to provide *depth* via IPA, a technique emphasising the value of utilising small samples. The philosophy underpinning IPA is that:

> "research should be judged first and foremost on how illuminating it is of the particular cases studied and that the micro-level theorising should be richly informative of those particular individuals and may well be fairly modest in it's claims to generalisation" (Smith, 1999, p 413).

Brocki and Wearden (2006) provide a review of participant numbers utilised in IPA and as Smith and Osborn (2003, p 54) note, "there is no right sample size". In addition, there is a growing consensus within qualitative psychological research towards the use of smaller sample sizes (Smith, 2004).

6.8. Recommendations

This was a small scale in-depth qualitative research study, the findings whilst not necessarily transferable, merit further research possibly with greater participant numbers, obtained from a wider geographical area. Nevertheless, the findings are interesting and require consideration in both public and professional areas. For professionals, national guidelines relating to ovarian cancer (NICE, 2004) are available and there is an implication for improved training in primary care, with regard to ovarian cancer awareness. For the public, education on ovarian cancer is needed. With education, women will have more knowledge to ensure GPs are fully aware of all the signs and symptoms. A national campaign on the signs and symptoms of ovarian cancer would be beneficial. The majority of women encountered in the research, expressed a lack of awareness of the signs and symptoms of ovarian cancer. Women with insight were those who had known someone who had developed this disease. Those without knowledge commented on retrospective recognition of early symptoms such as bowel and bladder changes or increase in girth, but did not have the knowledge base to determine that together these factors required investigation.

6.9. Future research directions

There are implications for further research, in the area of practising and trainee GP's and nurse practitioners. Quantitatively knowledge of the disease could be obtained and qualitatively perceptions of issues in late presentation and interaction could be explored.

A national quantitative study on public knowledge and awareness of the signs and symptoms of ovarian cancer could be undertaken to gauge the current level of public knowledge in the area.

It would also be interesting to audit the referral patterns of GP's who had experience of women patients with a confirmed diagnosis of ovarian cancer to monitor any future changes in referral practice. As Dempsey and Bekker (2002) suggest that GPs may refer more patients to fast track or emergency admissions, if there was a future risk of 'missing' a diagnosis. This may be the case following experience of a patient with ovarian cancer, however this will also relate to women communicating to GPs signs and symptoms.

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Appendix 1
Narrative review references – included papers and stage 2 excluded papers

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Power J.M. (2005). *Qualitative study examining psychosocial distress, coping and social support across the stages and phases of epithelial ovarian cancer.* Proquest Dissertations and Theses. York University: Canada. Publication Number: AAT MR11878. (Paper from this thesis used in narrative review)

Smith, A. (2008). Whisperings of Ovarian Cancer: Acknowledging Women's Voices. *Clinical Journal of Oncology Nursing,*12 (6):913-920.

Swenson, M.M., MacLeod, J.S., Williams, S.D. Miller, A.M.& Champion, V.L. (2003). Quality of living among germ cell cancer survivors, a narrative analysis. *Oncology Nursing Forum,* 30 (3): 48-54. Online exclusive, Retrieved07/05/2009 from http://www.ons.org/publications/journals/ONF/Volume30/Issue3/3003380.asp

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Ziebland, S., Evans, J., McPherson, A., Ziebland, S., Evans, J. & McPherson, A. (2006). The choice is yours? How women with ovarian cancer make sense of treatment choices. *Patient Education and Counseling,* 62:361-367.

2nd stage excluded

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Appendix 2: Narrative literature review - data extraction form

Title of Paper
Author(s)
Date & Journal
Location of study
Sample

Stated Aims

Epistemological perspective

Theoretical perspective

Method of data collection

Method of data analysis

Systematic

All data taken into account

Grounded in data

Themes

Discussion for and against interpretations

Outcomes

Transparency

Credibility, reliability, validity

Transferability

Researcher/process reflective

Appendix 3
Pilot Phase One Study

Cheshire West NHS
Primary Care Trust

SOUTH CHESHIRE LOCAL RESEARCH ETHICS COMMITTEE
comprising three sub-Committees in Chester, Crewe and Macclesfield

19th July 2002

Ms Mary Fisher-Morris
Research & Practice Development Co-ordinator
Clinical Audit
T-Block
Countess of Chester Hospital NHS Trust
Liverpool Road
CH2 1UL

Dear Ms Fisher-Morris,

Application Number: C259/02
Title: The Enigma of Ovarian Cancer – A study following patients as they traverse their treatment trajectory.

Thank you for your letter received on 4th July 2002, supplying amendments as requested by Chester Sub-Committee of South Cheshire LREC at the meeting held on Wednesday 22nd May 2002. The Chairman, acting under delegated authority, is satisfied that all the points raised have been addressed. There is therefore no objection on ethical grounds to the above named study. This study is **Approved.**

Conditions of Approval

- Any amendments to the study must be approved by this committee
- The study must start within three years of the date of this letter
- Any serious unexpected adverse reactions must be notified to the committee
- You complete the interim report form sent to you at the end of each year
- You complete a final report at the end of the study

The following items were reviewed in connection with the above study.

Ability of Investigator and staff to perform the proposed research: Approved

Suitability of the premises and facilities: Approved

Protocol: Approved

Protocol Amendments: N/A

Methods of Initial Recruitment to Study: Approved

Compensation for Investigator's Participation: N/A

continued…..

Patient Information Sheet	Approved amended patient information sheet (No version number or date given, therefore, designated Version 2 dated July 2002)
Patient Consent Form	Approved
Treatment of Subjects	Approved
Compensation for Subjects Participation	*N/A*
Other	

We wish you every success with your study.

Yours sincerely

Approved by Chairman
Signed by Administrator

Dr Noel Murphy
Chairman, Chester Sub-Committee of South Cheshire LREC
Research Ethics Administration Office
Room 34
Cheshire West Primary Care Trust
1829 Building
Countess of Chester Health Park
Liverpool Road
Chester CH2 1HJ

Tel: 01244 650334
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Email: susan.thompson@messa.scheshire-ha.nwest.nhs.uk

South Cheshire Local Research Ethics Committee is fully compliant with "the International Committee on Harmonisation/Good Clinical Practice (ICH) Guidelines for the Conduct of Trials Involving the participation of Human Subjects" as they relate to the responsibilities, composition, function, operations and records of an Independent Ethics Committee.

Appendix 4
Pilot Phase One Study

Cheshire Research Ethics Committee
Research Ethics Office
Victoria Building
Bishop Goss Complex
Rose Place
Liverpool
L3 3AN

Telephone: 0151 330 2070
Facsimile: 0151 330 2075

15 June 2009

Ms Mary Fisher-Morris
Research & Practice Development Co-ordinator
Clinical Audit
T-Block
Countess of Chester Hospital NHS Trust
Liverpool Road
Chester
CH2 1UL

Dear Ms Fisher-Morris

Title: The Enigma of Ovarian Cancer – A study following patients as they traverse their treatment trajectory.

REC reference: C259/02

Thank you for your enquiry dated 15 June 2009.

We can confirm that it was a condition of ethical approval of the above study that all correspondence to participants should be produced on hospital letter headed paper.

Statement of Compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK

Yours Sincerely

R G Emmett
Committee Co-ordinator

Appendix 5
Pilot Phase One Study

Countess of Chester Hospital NHS
NHS Foundation Trust

Research & Clinical Audit
General Wing
Countess of Chester Hospital
The Countess of Chester Health Park
Liverpool Road
Chester CH2 1UL

Telephone: 01244 365000
Direct Line 01244 365243
Email – mary.fisher-morris@coch.nhs.uk

[date]

Dear [ ],

Thank you very much for considering taking part in the research towards my Ph.D thesis. I look forward to meeting with you.

I have enclosed an information sheet to let you know more about the research, a brief questionnaire and a research consent form.

I would like to meet with you if possible the week beginning [ ]. I will meet with you at any time to suit you and in a location which is easier for you, such as a private room in the hospital, or your home. Please get in touch by letter or telephone, with the best time and place for you. I will telephone you to confirm our meeting.

When we meet, we will have time to discuss any questions you may have about the research. If you agree to participate then you can sign the consent form and we will both keep a copy.

If you have any queries, please get in touch with me.

Yours Sincerely

Mary Fisher-Morris
Head of Research & Clinical Audit.
Direct Line: 01244 365243

Appendix 6
Pilot Phase One Study

Countess of Chester Hospital NHS
NHS Foundation Trust

Patient Information Sheet

You are being invited to take part in a research study. Before you decide it is important for you to understand why this research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask me if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The aim of the research is to discover women's perceptions regarding their diagnosis and treatment, from their own personal experiences. You will have the opportunity to discuss your views during a confidential personal interview. It is hoped that the information from the study will help improve the quality of service women receive.

Do I have to take part?

It is entirely up to you to decide whether or not to take part. If you do decide to take part, you will be asked to sign the consent form enclosed with this sheet and return it to me. A copy will be returned to you to keep. You are free to decide to withdraw at any time, without giving any reason, and this will in no way affect the standard of care you receive.

What will happen to me if I take part?

A date and time decided by you will be selected, and a suitable venue arranged. This may be a private room in the hospital or outside of the Trust, if you wish. We can arrange this personally if you decide to participate. If you agree, our interview will be tape recorded and we will discuss areas of interest as outlined in this information sheet and also any other areas you think are important. This interview will be strictly confidential and can stop at any time you wish, but generally will last for approximately 1 hour.

What are the possible benefits of taking part?

During the interview it is hoped that you would feel free to discuss all aspects of your experience, care and treatment on an informal and strictly confidential basis. It is important that you feel free to relate your personal experiences and interpretations of how you felt, as a patient throughout your diagnosis and treatment. You will have the opportunity through the research to describe what patients really experience and feel.

Will my part in the study be kept confidential?

All information collected about you will be strictly confidential. Any information which is used in the research will be anonymised. That is it will have any personal identifiable information removed, your name, age, address etc. All information will be kept in a locked cabinet to which only the researcher has access. It will be destroyed 2 years after the research is completed.

What will happen to the results of the study?

The research is being undertaken for a Doctor of Philosophy degree (Ph.D), at the University of Liverpool. It is hoped to publish the results in medical journals. Any information you contribute will be anonymised and you will not be identified.

Who is organising and funding the research?

The researcher is funded by the Countess of Chester NHS Foundation Trust and is registered with the University of Liverpool as a Ph.D student.

Who has reviewed this study?

The Research Ethics Committee at *Chester reviewed* and approved the study.

Contact for further information

Mary Fisher Morris R.G.N., B.A.Hons, M.A.Econ.

Research & Clinical Audit,
Countess of Chester NHS Foundation Trust.
Liverpool Road,
Chester CH2 1UL

Telephone: 01244 365243
Email: mary.fisher-morris@coch.nhs.uk

Appendix 7

Pilot Phase One Study

Ovarian Questionnaire

The information in this questionnaire is strictly confidential and any information used in the research will be completely anonymous and you will not be able to be identified. Please answer any questions below you feel able to and add any comments you think may be relevant.

Name and address (optional):

This will be deleted from any data used from the research and is for the researchers personal records only.

Age: Occupation:
Working or retired:

Did you ever take a contraception pill – if so for approx how many years?

Have you ever been on HRT – if so for how long?

What was the symptom which made you visit the doctor and why?

How long had you had noticed this symptom or that it 'wasn't right'?

On the first visit, what was your G.P's initial opinion/diagnosis? Were you examined?

Date the diagnosis was given to you and by whom?

How long was it from the very first symptom you noticed, to diagnosis from the gynaecologist? (approx)

Did you have any knowledge of ovarian cancer before you were diagnosed?

Did you seek any information on ovarian cancer on the internet after diagnosis?

From the list below, what were the first symptoms you remember experiencing?
Please include anything at all you think may be relevant.

Pain – specify where and type

Changes in waterworks-e.g. frequency, pain, infection...

Change in bowel actions – constipation, diarrhoea, pain etc....

Swelling in abdomen –for how long did you notice your tummy getting bigger?

Wind

Vaginal discharge

Gaining or losing weight

Nausea/indigestion

Pain or discomfort with sex

Anything else you noticed as abnormal?

Thank you very much for giving your time and this information.

Would you be willing to have a personal interview with the researcher – Mary Fisher-Morris to discuss your experiences? Please read the information sheet again to help you decide and telephone, if you wish to discuss anything before deciding?

Please circle your answer YES NO

Appendix 8
Pilot Phase One Study
INTERVIEW FIELD NOTES TEMPLATE

Interviewee:
Date: Time: Location: Duration:

Early symptoms identified
time span from this to diagnosis

Personal response
what triggered GP visit, P interpretation of what was wrong

GP response
examined, tests

Interaction with GP
impressions, feelings, confidence, liked/disliked, satisfied /dissatisfied

Knowledge of Ovarian Cancer
pre and post diagnosis

Diagnosis where, when by whom

Diagnosis P *response, response of family/friends, specifically partner*

Treatment - personal interpretations

Physical issues - personal feelings/thoughts

Psychologically Issues
dealing with treatment, coping strategies

Perceptions/Opinions of experiences
Of consultant opinion and P opinion pre and post treatment
Positive, negative, other important issues

Things P would want to change
Pre and post diagnosis

Discuss how P rationalise/explain experience

Understanding of diagnosis
meanings to P

Discuss advice P give to another woman newly diagnosed with ovarian cancer

MFM reflections on the person, their background and medical history

Appendix 9
Phase Two Study

Countess of Chester Hospital NHS
NHS Foundation Trust

Research & Clinical Audit Department,
Main Corridor,
General Hospital Building,
Countess of Chester Health Park,
Liverpool Road,
Chester, CH2 1UL.
Direct line -Tel 01244 365243
Email- mary.fisher-morris@coch.nhs.uk

20th August. 2007

Dear Mr. Emmett,

Application Number C259/02

Title; The Enigma of Ovarian Cancer- a study following patients as they traverse their treatment trajectory.

Following my viva this month, the examiners have requested I recruit and interview several more participants to my study; they feel more interviews are needed. This is an ongoing study from my original ethics application and I will be using the same patient information sheet and consent forms and following the same method of enquiry. I have also notified the Trust R&D Committee of my intentions.

Do I need to complete any further ethics documentation?

Regards

Mary Fisher-Morris
Head of Research & Clinical Audit.

Appendix 10
Phase Two Study

Cheshire Research Ethics Committee
Research Ethics Office
Victoria Building
Bishop Goss Complex
Rose Place
Liverpool
L3 3AN
Telephone: 0151 330 2070
Facsimile: 0151 330 2075

21 August 2007

Ms Mary Fisher-Morris
Research & Practice Development Co-ordinator
Clinical Audit
T-Block
Countess of Chester Hospital NHS Trust
Liverpool Road
Chester
CH2 1UL

Dear Ms Fisher-Morris

Title: The Enigma of Ovarian Cancer – A study following patients as they traverse their treatment trajectory.

REC reference: C259/02

Thank you for notifying the Committee that the study will be extended beyond that specified in the application form.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require ethical review by the Committee and may be implemented immediately, provided that it does not affect the management approval for the research given by the R&D Department for the relevant NHS organisation.

Statement of Compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK

Yours Sincerely

R G Emmett
Committee Co-ordinator

Appendix 11
Phase Two Study

Cheshire Research Ethics Committee
Research Ethics Office
Victoria Building
Bishop Goss Complex
Rose Place
Liverpool
L3 3AN

Telephone: 0151 330 2070
Facsimile: 0151 330 2075

15 June 2009

Ms Mary Fisher-Morris
Research & Practice Development Co-ordinator
Clinical Audit
T-Block
Countess of Chester Hospital NHS Trust
Liverpool Road
Chester
CH2 1UL

Dear Ms Fisher-Morris

Title: The Enigma of Ovarian Cancer – A study following patients as they traverse their treatment trajectory.

REC reference: C259/02

Thank you for your enquiry dated 15 June 2009.

We can confirm that it was a condition of ethical approval of the above study that all correspondence to participants should be produced on hospital letter headed paper.

Statement of Compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK

Yours Sincerely

R G Emmett
Committee Co-ordinator

Appendix 12
Phase Two Study

Countess of Chester Hospital NHS
NHS Foundation Trust

Research & Clinical Audit
General Wing
Countess of Chester Hospital
The Countess of Chester Health Park
Liverpool Road
Chester CH2 1UL

Telephone: 01244 365000
Direct Line 01244 365243
Email – mary.fisher-morris@coch.nhs.uk

[date]

Dear [ ],

Thank you very much for considering taking part in the research towards my Ph.D thesis. I look forward to meeting with you.

I would like to meet with you if possible the week beginning [ ]. I will meet with you at any time to suit you and in a location which is easier for you, such as a private room in the hospital, or your home. Please get in touch by letter or telephone, with the best time and place for you. I will telephone you to confirm our meeting.

I have enclosed an information sheet to let you know more about the research and also a research consent form. When we meet, we will have time to discuss any questions you may have about the research. If you agree to participate then you can sign the consent form and we will both keep a copy.

If you have any queries, please get in touch with me.

Yours Sincerely

Mary Fisher-Morris
Head of Research & Clinical Audit.
Direct Line: 01244 365243

Appendix 13
Phase Two Study

Countess of Chester Hospital NHS
NHS Foundation Trust

Patient Information Sheet

You are being invited to take part in a research study. Before you decide it is important for you to understand why this research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask me if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The aim of the research is to discover women's perceptions regarding their diagnosis and treatment, from their own personal experiences. You will have the opportunity to discuss your views during a confidential personal interview. It is hoped that the information from the study will help improve the quality of service women receive.

Do I have to take part?

It is entirely up to you to decide whether or not to take part. If you do decide to take part, you will be asked to sign the consent form enclosed with this sheet and return it to me. A copy will be returned to you to keep. You are free to decide to withdraw at any time, without giving any reason, and this will in no way affect the standard of care you receive.

What will happen to me if I take part?

A date and time decided by you will be selected, and a suitable venue arranged. This may be a private room in the hospital or outside of the Trust, if you wish. We can arrange this personally if you decide to participate. If you agree, our interview will be tape recorded and we will discuss areas of interest as outlined in this information sheet and also any other areas you think are important. This interview will be strictly confidential and can stop at any time you wish, but generally will last for between 1 and 2 hours.

What are the possible benefits of taking part?

During the interview it is hoped that you would feel free to discuss all aspects of your experience, care and treatment on an informal and strictly confidential basis. It is important that you feel free to relate your personal experiences and interpretations of how you felt, as a patient throughout your diagnosis and treatment. You will have the opportunity through the research to describe what patients really experience and feel.

Will my part in the study be kept confidential?

All information collected about you will be strictly confidential. Any information which is used in the research will be anonymised. That is it will have any personal identifiable information removed, your name, age, address etc. All information will be kept in a locked cabinet to which only the researcher has access. It will be destroyed 2 years after the research is completed.

What will happen to the results of the study?
The research is being undertaken for a Doctor of Philosophy degree (Ph.D), in the Clinical Psychology Department, in the Faculty of Medicine, at the University of Liverpool. It is hoped to publish the results in medical journals. Any information you contribute will be anonymised and you will not be identified.

Who is organising and funding the research?
The researcher is funded by the Countess of Chester NHS Foundation Trust and is registered with the University of Liverpool as a Ph.D student.

Who has reviewed this study?
The Research Ethics Committee at Chester reviewed and approved the study.

Contact for further information

Mary Fisher Morris R.G.N., B.A.Hons, M.A.Econ.

Research & Clinical Audit,
Countess of Chester NHS Foundation Trust.
Liverpool Road,
Chester CH2 1UL

Telephone: 01244 365243
Email: mary.fisher-morris@coch.nhs.uk

Appendix 14
Phase Two Study
INTERVIEW FIELD NOTES TEMPLATE

Interviewee:
Date: Time: Location: Duration:

Early symptoms identified
time span from this to diagnosis

Personal response
what triggered GP visit, P interpretation of what was wrong

GP response
examined, tests

Interaction with GP
impressions, feelings, confidence, liked/disliked, satisfied /dissatisfied

Knowledge of Ovarian Cancer
pre and post diagnosis

Diagnosis where, when by whom

Diagnosis P *response, response of family/friends, specifically partner*

Treatment - personal interpretations

Physical issues - personal feelings/thoughts

Psychologically Issues
dealing with treatment, coping strategies

Perceptions/Opinions of experiences
Of consultant opinion and P opinion pre and post treatment
Positive, negative, other important issues

Things P would want to change
Pre and post diagnosis

Discuss how P rationalise/explain experience

Understanding of diagnosis
meanings to P

Discuss advice P give to another woman newly diagnosed with ovarian cancer

MFM reflections on the person, their background and medical history